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**“There’s always going to be that political filtering”: The emergence of Second Generation Surveillance for HIV/AIDS, data from Uganda, and the relationship between evidence and global health policy**



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## Declaration of originality

I, Douglas Alexander Richards, declare that the work presented in this PhD thesis is my own and that it has not been submitted for any other degree or professional qualification:

Signed: \_\_\_\_\_

Date: \_\_\_\_\_

## Abstract

**Background:** It is widely acknowledged that Uganda was the first country in sub-Saharan Africa to experience a significant decline in HIV seroprevalence in the 1990s. Framed as the initial 'success story' in the history of the global HIV/AIDS pandemic, the behavioural mechanisms and policies accounting for the Ugandan HIV decline have been extensively debated over the past 25 years. With reference to broader debates about the role of evidence in policy, this thesis aims to examine contested explanations for the decline in HIV prevalence in Uganda and the role of evidence in the development of global HIV prevention policy in the 1990s.

The thesis examines diverse explanations for Uganda's HIV decline and how these came to be framed in the context of the emergence of Second Generation Surveillance (SGS), a global HIV/AIDS surveillance framework introduced by UNAIDS/WHO in 2000. Official accounts describe SGS as having been developed on the basis of Ugandan behavioural evidence presented during a key meeting of HIV/AIDS policymakers which took place in Nairobi in 1997. This meeting provides a focal point for examining the role of evidence in global HIV prevention policy and the relationship between evidence and policy pertaining to low income countries in the 1990s.

**Methods:** A review of UNAIDS/WHO documents and 29 in-depth interviews with HIV/AIDS experts from Uganda and international organisations were analysed.

**Results:** UNAIDS documents present SGS as a technocratic, problem-solving response to limitations in established HIV surveillance approaches, developed at a UNAIDS-sponsored workshop in Nairobi, Kenya, in 1997. These official accounts present the emergence of SGS as evidence-based and reflecting a clear consensus that developed during the Nairobi workshop. While interview data suggest agreement around the need for improved HIV surveillance systems, they indicate a more complex picture in terms of the



extent to which SGS was evidence-based and highlight contested interpretations of this evidence among HIV experts.

Findings from interviews suggest that the introduction of SGS by UNAIDS/WHO may be understood as serving both technical and broader strategic purposes. As indicated in UNAIDS/WHO policy documentation, SGS was intended to improve older global HIV surveillance methodologies via the triangulation of multiple data sources. The introduction of SGS also appears to have served two broader purposes, functioning as something akin to a marketing tool to help promote the institutional identity of UNAIDS, while also signalling a shift towards a 'multisectoral' approach that aimed to unify epidemiological and social scientific disciplinary approaches.

While interviewees' accounts coincide in describing a decline in HIV prevalence during the 1990s, they present divergent interpretations of this evidence which became significant in the development of SGS. One interpretation focused on a reduction in multiple partnerships within the Ugandan population as the key change driving the decline in HIV prevalence, while a contrasting explanation focused on increased use of condoms as the primary cause of this decline. Interviewees' accounts suggest a process of competition, whereby different actors sought to secure the primacy of their interpretation in institutional understandings of Uganda's HIV decline and in the development of SGS. Claims of disciplinary bias and institutional marginalisation appear to have contributed to the subordination of explanations focused on a decline in multiple sexual partners, while the policy entrepreneurship of one key actor appears influential in explaining the ascendancy of explanations focused on increased condom use. Despite these contestations around the evidence used to inform the development of SGS, UNAIDS documents and peer-reviewed publications from this period emphasise one interpretation (that of increased condom uptake) which thus appears as the official explanation for the success of HIV control in Uganda.

The transition from the WHO's Global Programme on AIDS (GPA) to UNAIDS, and the initiation of a multisectoral HIV prevention approach,

appear as important contextual and institutional influences in the interpretation of evidence for Uganda's HIV decline. The failure of the partnership reduction explanation to align with the evolving institutional and political orthodoxy, and the potential for this explanation to challenge UNAIDS' new focus on multisectoral HIV prevention, may help to explain why it did not inform subsequent HIV/AIDS policy and does not appear in official accounts of SGS's development. In contrast, explanations focused on increased condom use were consistent with UNAIDS' HIV prevention policy agenda (including its emphasis on multisectoral approaches) and appeared to reinforce the organisation's need for increased financial resources to mitigate HIV/AIDS via the distribution and promotion of condoms.

**Discussion:** This study demonstrates that the development of SGS, and the politics of evidence supporting its introduction, are more complex than existing UNAIDS/WHO accounts describe. Official explanations of the development of SGS provide a simplistic account of how evidence informed policy in a linear and rational way. In contrast, findings from this thesis suggest that SGS served multiple policy functions (i.e. marketing, promotion of institutional credibility, and a demonstration of disciplinary integration) in the context of the recently-formed UNAIDS, and that the role and interpretation of evidence in this context were highly contested. Consistent with the work of Kingdon (1995) and more recently Stevens (2007), this study suggests that personal, political and institutional factors play important roles in shaping how evidence is presented and linked with policy. These findings suggest that more nuanced understandings of the relationship between evidence and policy are needed to explain HIV/AIDS policy development within both sub-Saharan African and at a global level.

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## List of acronyms

<b>ABC</b>	Abstinence, Being Faithful and Condom Use.
<b>AIDS</b>	Acquired Immunodeficiency Syndrome.
<b>ANC</b>	Antenatal Clinic.
<b>BSS</b>	Behavioural Surveillance Surveys.
<b>CSWs</b>	Commercial Sex Workers.
<b>DHS</b>	Demographic and Health Surveys.
<b>DOTS</b>	Directly Observed Treatment Short-Course.
<b>EBM</b>	Evidence-Based Medicine.
<b>EBPH</b>	Evidence-Based Public Health.
<b>EBPM</b>	Evidence-Based Policymaking.
<b>ECOSOC</b>	Economic and Social Council.
<b>GBD</b>	Global Burden of Disease.
<b>GPA</b>	Global Programme on AIDS.
<b>GRADE</b>	Grades of Recommendation, Assessment, Development, and Evaluation.
<b>HICs</b>	High-Income Countries.
<b>HIV</b>	Human Immunodeficiency Virus.
<b>HSV-2</b>	Herpes Simplex Virus—Type 2.
<b>IDUs</b>	Injecting Drug Users.
<b>LICs</b>	Low-Income Countries.
<b>LMICs</b>	Low- and Middle-Income Countries.

<b>MSM</b>	Men Who Have Sex With Men.
<b>SGS</b>	Second Generation Surveillance.
<b>SSPS</b>	School of Social Political Science.
<b>STI</b>	Sexually Transmitted Infections.
<b>UN</b>	United Nations.
<b>UNAIDS</b>	Joint United Nations Programme on HIV / AIDS.
<b>UNCST</b>	Uganda National Council of Science and Technology.
<b>UNDP</b>	United National Development Programme.
<b>USAID</b>	United States Agency for International Development.
<b>WHA</b>	World Health Assembly.
<b>WHO</b>	World Health Organisation.

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# CHAPTER ONE: Introduction

## 1.1 Background to the research

It is commonly acknowledged within the global health literature that Uganda was the first country in sub-Saharan Africa to experience a significant decline in HIV seroprevalence in the 1990s (Genius & Genius: 2005; Kirby: 2008; Okware et al: 2001; Slutkin et al: 2006; Stoneburner & Low-Beer: 2004). Historic epidemiological data indicate that Uganda successfully reversed a generalised, high prevalence epidemic from as high as 30% in 1992 to as low as 6% in 2000 among women attending certain urban antenatal clinics (Merson: 2006: pp. 333). Framed as the initial 'success story' in the history of the global HIV/AIDS pandemic, it is thus unsurprising that considerable academic effort has been made to determine the precise cause of the decline in HIV prevalence in Uganda (Merson: 2006: pp. 333). Indeed, the specific behavioural mechanisms accounting for the HIV decline in Uganda, have been subject to extensive debate during the past 25 years and there has been "much controversy around the relative importance of various components of sexual behavioural change—namely abstinence, partner reduction and condom use in contributing to the decline in HIV prevalence" (Merson: 2006: pp. 333).

This thesis engages with these debates to examine how explanations advanced for the decline in Ugandan HIV prevalence were contested and the role of evidence in the development of global HIV prevention policy in the 1990s. To facilitate this analysis, this thesis focuses on diverse explanations for Uganda's HIV decline and how these came to be framed in the context of the emergence of Second Generation Surveillance (SGS), a global HIV/AIDS surveillance policy framework initiated by UNAIDS/WHO in 2000. Official accounts describe SGS as having been developed on the basis of Ugandan behavioural evidence presented at a key meeting of HIV/AIDS policymakers which took place in Nairobi in 1997. This meeting, and the discussions

surrounding it, thus provides a focal point for examining the role of evidence in global HIV prevention policy development and the relationship between evidence and policy pertaining to low income countries (LICs) in the 1990s. Prior to advancing, it is required to define SGS and to explain its significance within debates regarding the HIV decline in Uganda and to wider developments in global HIV/AIDS prevention policy in the 1990s.

## 1.2 Defining Second Generation Surveillance

Formally introduced by UNAIDS/WHO in 2000, SGS has been the principal surveillance policy framework to monitor changes in the ongoing HIV/AIDS epidemic. It is claimed by UNAIDS/WHO that SGS was needed as older HIV/AIDS surveillance approaches were ill-equipped to capture the diversity of HIV/AIDS epidemics around the world (UNAIDS/WHO: 2000: pp. 1). Reflecting upon ten years of experience since the publication of the original WHO Global Programme on AIDS (GPA) guidelines on HIV/AIDS surveillance, UNAIDS/WHO depicted that HIV/AIDS epidemics were much more heterogeneous than originally conceived, affecting different populations in different ways in distinct geographical areas (UNAIDS/WHO: 2000: pp. 2).

In reaction to the acknowledged distinctiveness of HIV/AIDS epidemics, a global enhancement in HIV/AIDS surveillance policy was seen as required and SGS was formally initiated by UNAIDS/WHO as the way forward. Significantly, improvements in global HIV/AIDS surveillance were required as the HIV/AIDS pandemic, at the time of the introduction of SGS, was increasing at the global level (excluding The Republic of Uganda and The Kingdom of Thailand) and existing HIV/AIDS surveillance systems were identified as failing to capture information about risk behaviours that were contributing to this global rise. Additionally, in the early years of HIV/AIDS surveillance, systems monitoring the HIV/AIDS epidemic focused mainly on tracking the HIV virus via antenatal clinic (ANC) sentinel surveillance and AIDS case reporting (Garcia-Calleja et al: 2006: pp. 64; Hladik et al: 2008: pp.

504). While these data sources were considered to be a useful component of formative HIV/AIDS surveillance approaches, they merely recorded historical HIV infections and were seen as missing an opportunity to give early warnings of the potential for HIV infection in specific at-risk groups (at-risk groups including: Commercial Sex Workers (CSWs), Men Who Have Sex With Men (MSM) and Injecting Drug Users (IDUs)) (UNAIDS/WHO: 2000: pp. 4).

In reaction to the acknowledged limitations of older HIV/AIDS surveillance approaches, SGS was intended to improve existing HIV/AIDS surveillance methodologies via the triangulation of multiple data sources, with behavioural surveillance data being incorporated as an adjunct to existing serological surveillance information. Such incorporation aimed to improve both HIV data collection methodologies and subsequent HIV/AIDS surveillance data analysis, which, in turn, could enhance planning and the evaluation of HIV prevention activities (UNAIDS/WHO: 2000: pp. 2; Rehle et al: 2004: pp. 122). For a pathogenic viral disease that is mainly transmitted by risk-taking behaviours, it was appropriate for any update in global HIV/AIDS surveillance approaches to incorporate information about behavioural risk and this was precisely what SGS intended to accomplish. This commitment to the integration of behavioural data into existing HIV/AIDS surveillance information is reflected within an official definition of SGS advanced by the WHO on its website:

Second generation surveillance for HIV/AIDS is the regular, systematic collection, analysis and interpretation of information for use in tracking and describing changes in the HIV/AIDS epidemic over time. Second generation surveillance for HIV/AIDS also gathers information on risk behaviours, using them to warn of or explain changes in levels of infection. As such, second generation surveillance includes, in addition to HIV surveillance and AIDS case reporting, STI surveillance to monitor the spread of STI in populations at risk of HIV and behavioural surveillance to monitor trends in risk behaviours over time (WHO: 2015a).

The introduction of SGS aimed to improve older HIV/AIDS surveillance approaches via the triangulation of multiple data sources with behavioural

data being incorporated as a core component of this enhanced global HIV/AIDS surveillance policy framework. Indeed, the addition and concurrent comparison of behavioural data to existing serological data sources is considered to be an essential and integral component of the SGS approach (Rehle et al: 2004: pp. 122; Pisani: 2006: pp. 27). This is as articulated by UNAIDS/WHO (2000):

A central tenet of second generation surveillance is that behavioural and biological surveillance data be used to inform and explain one another. The power of the two sets of information to illuminate real trends in the epidemic and the behaviours that spread it is greatly increased if they are designed from the start to be used together (UNAIDS/WHO: 2000: pp. 36).

Acknowledging the centrality of behavioural surveillance data within the SGS approach, it is useful to clarify why this particular kind of data was depicted as so significant in purportedly improving upon older HIV/AIDS surveillance methodologies. The significance afforded to behavioural surveillance data within the SGS approach comes from its professed capacity to not just identify how many people are infected with HIV (which is ascertained through seroprevalence data) but to examine *why* they are infected (UNAIDS: 1998a: pp. 5). Capturing information about behavioural risk, which older HIV/AIDS surveillance approaches failed to accomplish, was a central component to SGS. The SGS guidelines published in 2000 were therefore presented as addressing the limitations and deficiencies of earlier HIV/AIDS surveillance efforts by integrating, most critically, studies of the sexual behaviour of individuals at risk of acquiring and transmitting HIV (Bayer & Fairchild: 2004: pp. 3).

The rationale for integrating behavioural surveillance data, alongside existing serological sources, also stems from its perceived capacity to enhance HIV/AIDS decision-making on multiple levels. The analysis of behavioural data by public health officials is seen as helpful in explaining variations in HIV prevalence whilst also elucidating who is at the greatest risk of acquiring HIV and why (Family Health International: 2000: pp. 2 – 3). Behavioural data is therefore regarded as valuable in helping program

planners and communities tailor existing HIV prevention activities and developing effective public health interventions to interrupt the chain of HIV transmission (Family Health International: 2000: pp. 2 – 3). Shifts in the pattern of risk can also be ascertained via the collection of behavioural surveillance data, and the analysis of behavioural data can give public health officials an indication of the success of HIV prevention activities aimed at promoting safe behaviour at the population-level (Family Health International: 2000: pp. 2 – 3). Table 1 summarises what UNAIDS/WHO regarded as the limitations of older HIV/ AIDS surveillance approaches and the strengths of SGS:

**Table 1: Limitations of older HIV/AIDS surveillance approaches and strengths of SGS**

<b>Limitations of older HIV/AIDS surveillance approaches</b>	<b>Strengths of SGS</b>
Failure to monitor risk behaviours that provide warning signs for the spread of HIV.	Better understanding of trends over time.
Useful information from other data sources is often ignored.	Better understanding of the behaviours driving the HIV epidemic in a country.
Surveillance resources are often targeted in the general population where little infection exists, while at-risk sub-populations are neglected.	Surveillance more focused on sub-populations at highest risk of infection.
Existing systems have difficulty explaining changes in the levels of HIV infection in mature epidemics or in countries where therapy exists.	Flexible surveillance that moves with the needs and state of the epidemic and better use of surveillance data to increase understanding and to plan prevention/care.

(Sources derived from UNAIDS/WHO: 2000: pp. 2 – 3)



In summary, it can be stated that SGS aimed to build upon established HIV/AIDS surveillance approaches via the triangulation of multiple data sources—with behavioural data being incorporated as a key component of this strengthened global HIV/AIDS surveillance policy framework. Via the integration and analysis of multiple data sources, the adoption of SGS was intended to create a more comprehensive approach to HIV/AIDS surveillance, which it was hoped could ultimately permit decision-makers to understand better the evolution of HIV transmission and its underlying behavioural determinants at the national, regional and global levels. According to UNAIDS/WHO, SGS aimed to build upon the lessons learned in the first decade of HIV/AIDS surveillance and the approach did not propose any radically new methods of data collection. Rather, SGS aimed to focus established HIV/AIDS surveillance methods on appropriate populations and sub-populations, in order to combine them in ways that had the greatest explanatory power (UNAIDS/WHO: 2000: pp. 8). Formally introduced in the year 2000, at a time when HIV/AIDS was increasing in most countries globally, UNAIDS/WHO intended SGS to give countries affected by HIV/AIDS more information about their own epidemics in order to combat its spread (WHO: 2015a).

### 1.3 Rationale for using SGS to examine Uganda's HIV decline and global HIV prevention policy development in the 1990s

SGS has been used as a tool to examine contested explanations for the decline in HIV prevalence in Uganda and the role of evidence in the development of global HIV prevention policy for two reasons. First, the substantive evidence-base used by UNAIDS/WHO to support the formal introduction of SGS was primarily derived from sexual behavioural research findings that emerged from Uganda in the early to late 1990s (UNAIDS: 1998a: pp. 5). Furthermore, the sexual behavioural change evidence, used to support the formal introduction of SGS, were concurrently utilised to permit HIV/AIDS experts to understand the sexual behavioural change reasons that could account for the decline in HIV prevalence in Uganda in the 1990s (UNAIDS: 1998a: pp. 5). In fact, it was primarily the presentation of Ugandan

behavioural evidence at a UNAIDS funded HIV surveillance improvement workshop, held in Nairobi, Kenya between the 10<sup>th</sup> to the 13<sup>th</sup> of February 1997, that was used to illustrate the potential for utilising behavioural information to interpret serological trends in HIV infection—thus catalysing the idea for SGS (UNAIDS: 1998a: pp. 3). The centrality of Ugandan behavioural data at the workshop is reflected within UNAIDS Best Practice Collection policy documentation:

The workshop began by analysing a case study presentation by one of the participant countries, Uganda. Uganda has strong HIV serosurveillance systems which indicate a drop in HIV infection rates in the youngest age groups in urban areas. The country also has repeat behavioural surveys, all showing that those same age groups are delaying sexual activity and using more condoms than in the past. But the two types of surveillance, serological and behavioural, had not been previously examined together. The exercise of analysing both sets of data in conjunction provided a graphic illustration of how behavioural surveillance can be used to help explain results found in serosurveillance (UNAIDS: 1998a: pp. 3).

Ugandan behavioural data presented at the workshop have also been described within UNAIDS Best Practice Collection policy documentation as “the best data so far” (UNAIDS: 1998a: pp. 5) and the exhibition of Ugandan data was described by UNAIDS (1998a) as “the centerpiece of the workshop” (UNAIDS: 1998a: pp. 5). Acknowledging the significance afforded to Ugandan behavioural surveillance data presented at the Nairobi workshop, it is necessary to explain why behavioural data from this particular sub-Saharan African country took such a central role in supporting the introduction of SGS and the direction of subsequent global HIV/AIDS prevention policy in the 1990s.

The centrality of Ugandan data stemmed primarily from the duration of its availability, and the observation that HIV prevalence had actually declined in this country. Unlike other sub-Saharan African countries, Uganda was at the forefront of recognising that HIV/AIDS was a major public health issue early on the HIV/AIDS pandemic. In fact, the early acknowledgment of HIV/AIDS as a domestic policy problem resulted in the Ugandan

government taking action to fight HIV/AIDS both openly and directly (UNAIDS: 1998b: pp. 5). It also resulted in the Ugandan government obtaining financial and technical support from donors and international organisations to help combat HIV/AIDS (Slutkin et al: 2006: pp. 359). In the process of addressing HIV/AIDS as a domestic public health problem early on in the epidemic, Uganda was able to develop what was seen as a “strong” (UNAIDS: 1998b: pp. 3) HIV surveillance system, which therefore created long-term surveillance data that could be analysed by experts attending the UNAIDS funded HIV surveillance workshop in 1997. It is documented within UNAIDS (1998a) that social scientists from Uganda were able to present surveys of sexual behavioural change from 1989 and 1995, which gave experts attending the Nairobi workshop ideas about the sexual behavioural change reasons that were contributing to Uganda’s HIV seroprevalence decline of the early to mid-1990s. Importantly, the comparison of the 1989 and 1995 surveys on sexual behavioural change, combined with 300 small-scale sociological studies, have been reported as key sources of evidence which alerted decision-makers to the possibility of sexual behavioural change in various age groups in urban areas within the country (UNAIDS: 1998a: pp. 5). These sources of evidence are important for two reasons. First, the analysis of these behavioural data sources provided decision-makers with a basis for understanding the formative sexual behavioural changes that were contributing to Uganda’s HIV decline of the early to mid-1990s. UNAIDS (1998a) attributed this to a rise in age at first sex and increased condom use in urban areas:

Social scientists from Uganda were able to present surveys of sexual behaviour from 1989 and 1995. Although not perfectly comparable, these surveys gave an idea of changes in current behaviour in various age groups in urban areas. Together with evidence compiled from more than 300 smaller-scale sociological studies, the survey results strongly suggest a rise in age at first sex and more use of condoms in cities (UNAIDS: 1998a: pp. 5)

Secondly, the concurrent comparison of Ugandan serological data with Ugandan behavioural data provided the first illustration of how behavioural surveillance could be utilised to help explain results found in

serosurveillance and was therefore presented as validating the behavioural component of the SGS approach (UNAIDS: 1998a: pp. 3). Importantly, the substantive behavioural evidence-base which helped support the decision to introduce SGS came from Uganda. It is additionally clear that behavioural evidence, supporting the development of SGS, were also used to permit HIV/AIDS policymakers to understand the specific sexual behavioural change reasons that were contributing towards Uganda's HIV seroprevalence decline of the 1990s. Thus, discussions pertaining to the development of SGS, and its underlying Ugandan evidence-base, directly relate to broader discussions about the Ugandan HIV decline, its contested nature, and the subsequent direction of HIV/AIDS prevention policy in the 1990s. Therefore, a critical analysis of SGS enables an examination of how explanations advanced for the decline in Ugandan HIV prevalence were contested and why particular explanations informed the development of global HIV prevention policy in the 1990s.

The second reason for using SGS as a tool to examine the contested Ugandan HIV decline and the role of evidence in global HIV prevention policy development in the 1990s relates to simplistic, and therefore potentially problematic, accounts of its historical development that were advanced by UNAIDS/WHO from the late-1990s onwards. Significantly, official accounts that describe the development of SGS and its evidence-base have only been provided by UNAIDS/WHO (UNAIDS: 1998a; UNAIDS: 1998b; WHO/UNAIDS: 2000). Although useful in a descriptive sense, UNAIDS/WHO frame the development of SGS as a rational adaptation to older global HIV surveillance approaches. They assert that SGS emerged in reaction to the idea that behavioural surveillance data could be used to build upon older, serologically focused, HIV surveillance approaches in a seemingly rational manner. They also identify a seminal event in the development of SGS—namely the aforesaid UNAIDS sponsored HIV surveillance consensus building workshop held in Nairobi, Kenya in 1997:

Surveillance systems appropriate in the early days of the [HIV] epidemic need to be adapted and built upon as our knowledge

grows. UNAIDS sponsored the Nairobi workshop on improved surveillance with this in mind. The workshop succeeded in illustrating the potential for using behavioural data to interpret serological trends and in suggesting what countries might aim for in a “second generation” of surveillance activities (UNAIDS: 1998a: pp. 5).

This account raises questions as it gives the impression of a linear link between new forms of research-based evidence (behavioural surveillance data) and its rational synthesis by decision-makers towards the development of enhanced global HIV surveillance policy. Such a depiction invites critical appraisal given that the relationship between evidence and policy, particularly within the field of global HIV policy, is typically non-linear as political obstacles often impede the policy-uptake of research-based evidence (Hunsmann: 2012: pp. 1477). In the context of HIV policy, it has also been claimed that in numerous contexts, politics, ignorance and ideology can have a greater influence on HIV policy than do evidence and best practice. Despite the acknowledged political nature of HIV policy itself, there is astonishingly little published analysis on the political determinants of HIV policy—especially pertaining to low- and middle-income countries (LMICs) (Dickinson & Buse: 2008: pp. 1). Acknowledging that evidence rarely informs policy in a linear manner, and the noted political nature of HIV policy development itself pertaining to LMICs, it is required to examine critically the narrative advanced by UNAIDS (1998a) as it fails to reflect the complexity of the relationship between evidence and policy—particularly within the politicised field of HIV/AIDS. Moreover, documents produced by institutions, like UNAIDS/WHO, should not be assumed to be neutral sources of information as they often reflect unknown bias given that documents are written for some specific audience and some specific purpose (Yin: 2009: pp. 86 – 87).

Perhaps a surprising element of the SGS approach is the apparent disciplinary integration of the medical community and behavioural scientists, the relationship of which was acknowledged by UNAIDS (1998a) as problematic in the late-1990s:

Policy-makers are interested in levels of HIV infection because they want to be able to plan for the consequences of that infection. They also need to decide what to do to slow the spread of the virus, and want to judge the effectiveness of their past interventions...But there have traditionally been barriers between the medical community that governs seroprevalence and the social scientists who look at behaviour and what lies behind it, and those barriers are hard to break down (UNAIDS: 1998a: pp. 5)

The acknowledgement by UNAIDS (1998a) of established barriers between the medical community and social scientists, when SGS emerged in the late-1990s, raises interesting questions as competition between medical, and other health professionals, have been noted as influencing how certain forms of knowledge are accepted and others discarded in the process of developing policy (Bryant: 1998: pp. 89). Importantly, both disciplines approach the creation, analysis and evaluation of evidence according to their underlying epistemological worldviews, suggesting that competition between the two disciplines could have resulted in certain framings of Ugandan behavioural evidence being accepted as more credible, whilst others were potentially rejected, within the process of developing SGS itself. Moreover, at the time that SGS emerged, HIV/AIDS was mainly defined and framed through a biomedical paradigm, indeed, biomedical forms of knowledge dominated the discourse to HIV/AIDS policy in the early to late-1990s (Tarantola: 2000: pp. 1). The established biomedical dominance, at the time that SGS was developed, could have affected how individual decision-makers worked together and the noted barriers between the two disciplines may have influenced the way Ugandan evidence was used to support the development of SGS itself and broader debates surrounding HIV prevention policy development in the 1990s. Acknowledging these issues, it is therefore appropriate to examine competing claims about the Ugandan behavioural evidence used to support the development of SGS and explanations for the Ugandan HIV decline. It is also necessary to establish if the noted disciplinary barriers influenced the relationship between evidence and policy for SGS itself, and the subsequent development of HIV prevention policy in the 1990s.

## 1.4 Thesis aim

Via an analysis of the emergence of SGS, to examine contested explanations for the decline in HIV prevalence in Uganda and the role of evidence in the development of global HIV prevention policy.

## 1.5 Four research objectives

I) To review literature examining the relationship between evidence and health policy pertaining to sub-Saharan Africa, including literature examining the role of evidence in the formulation of HIV prevention policy, and the interpretation and use of Ugandan HIV surveillance data in the development of HIV prevention policy in the 1990s;

II) To examine developments in global HIV prevention policy in the 1990s, particularly the introduction of SGS, including the role and use of evidence from Uganda in this policy;

III) To examine competing interpretations of Ugandan sexual behavioural change evidence used to create formative explanations for Uganda's HIV seroprevalence decline;

IV) To examine how institutional and political context change influenced competing Ugandan sexual behavioural interpretations and subsequent HIV prevention policy development in the 1990s.

## 1.6 Organisation of the thesis

The next chapter aims to review academic literature to examine the role of evidence in the formulation of HIV prevention policy and to explore the interpretation, and use of, Ugandan HIV surveillance data in the formulation of HIV prevention policy in the 1990s. This is situated within the context of

wider discussions of the relationship between evidence and policy pertaining to LICs within sub-Saharan Africa. The chapter commences by defining and discussing key terms of central analytical relevance to the thesis, namely: evidence, evidence hierarchies, policy, the policymaking process and policy networks. It then offers an appraisal of existing literature that provides an overview of the relationship between evidence and policy within high income countries (HICs). A focused discussion about the use of evidence within policymaking and key issues that influence the utilisation of evidence within the field of public health will be given. The chapter then turns its attention to exploring the relationship between evidence and health policy pertaining to sub-Saharan African contexts, whilst inductively analysing factors that influence evidence/health policy dynamics within the region. A concise discussion about the strengths and limitations of the literature that has attempted to examine the relationship between evidence and policy pertaining to sub-Saharan Africa and HICs will be advanced.

An account of the methodological approaches selected to examine contested explanations for the decline in HIV prevalence in Uganda and the role of evidence in the development of global HIV prevention policy will be given within the third chapter. The chapter justifies the qualitative research design adopted for the study, the reasons supporting the use of a case-study approach, the function of documentary analysis, how participants were selected for interview, the tools used for data collection and the approach adopted for data analysis. It also outlines the process of acquiring Uganda National Council of Science and Technology (UNCST) research clearance. The process of addressing University of Edinburgh School of Social and Political Science (SSPS) ethical protocols that were secured prior to the data collection phase of this study will also be given. Epistemological and ontological reflections are discussed, and issues pertaining to researcher reflexivity are posited.

It is the analytical objective of the fourth chapter to examine developments in global HIV prevention policy in the 1990s and in particular, the introduction of SGS and the role and use of evidence from Uganda in this policy. The



chapter aims to examine the aforementioned Nairobi workshop in detail, to explore the underlying sources of evidence used to support the development of SGS itself and to locate the key actors involved with SGS's emergence. To achieve this, a detailed historical analysis of SGS and its evidence-base supported by interview material from HIV/AIDS experts who attended, or knew about, the workshop itself will be given. Such examination is required to address aspects of the core aim of this thesis, namely to examine contested explanations for the decline in HIV prevalence in Uganda and the role of evidence in the development of global HIV prevention policy in the 1990s.

Having unpacked the development of SGS and its evidence-base, the fifth chapter aims to examine how HIV/AIDS experts used Ugandan behavioural evidence to support the development of SGS and to create formative understandings of Uganda's HIV decline of the early to mid-1990s. A critical examination of a competition over opposing interpretations of Ugandan sexual behavioural change evidence will be given. Attention is fixed to the influence of complex legitimising and discrediting strategies used by HIV/AIDS experts to garner support for two competing sexual behavioural change explanations that could account for Uganda's HIV seroprevalence decline of the early to mid-1990s. In relation to the thesis as a whole, it is the aim of the fifth chapter to unpack the competitive nature of the Ugandan evidence supporting the development of SGS, whilst considering the implications of the competitive debate over Ugandan evidence – that occurred among HIV/AIDS experts – upon the relationship between evidence and policy in HIV/AIDS policymaking networks.

Chapter six aims to examine the influence of political and institutional adaptation upon competing explanations of Ugandan behavioural evidence advanced by HIV/AIDS experts within global and Ugandan level policymaking contexts. It explores the influence of developments in the approach to global HIV/AIDS prevention - namely multisectoralism - and how Ugandan evidence supporting the development of SGS, and formative accounts of Uganda's HIV decline, were influenced by political and institutional change. Via an exploration of the institutional and political

context – within which evidence supporting the development of SGS was mediated by HIV / AIDS experts – the chapter will enable the thesis to clarify the role of evidence used to support the formal development of SGS, whilst locating broad level factors that can influence the relationship between evidence and policy.

It is the aim of the seventh chapter to discuss the main empirical findings presented within the three results chapters, while reflecting upon the use of SGS as a case study to examine contested explanations for the decline in HIV prevalence in Uganda, the role of evidence in the development of global HIV prevention policy in the 1990s and the relationship between evidence and policy pertaining to sub-Saharan Africa. The chapter discusses the study's empirical contributions to existing accounts of SGS's development, its contributions to historical narratives of Uganda's HIV 'success' story and it engages with existing theoretical frameworks that have attempted to model the relationship between evidence and policy—in particular Stevens' (2007) evolutionary model. The limitations and strengths of the study are discussed and directions for future research are suggested.

Chapter eight advances the conclusions of the research project.

## CHAPTER TWO: Defining key terms and examining the role of evidence, including Ugandan surveillance data, in HIV prevention policy in the 1990s

### 2.1 Introduction to chapter

It is the aim of this chapter to review academic literature to examine the role of evidence, including Ugandan surveillance data, in HIV prevention policy development in the 1990s. Its secondary aim is to explore the relationship between evidence and health policy pertaining to sub-Saharan Africa, highlighting relevant theories of the relationship between evidence and health policy relating to LICs. The chapter will commence by defining key terms of analytical relevance to the thesis, specifically: ‘evidence’, ‘evidence hierarchies’, ‘policy’, the ‘policymaking process’ and ‘policy networks’. Once key terms are defined, an examination of established theoretical frameworks that attempt to model the relationship between evidence and policy—drawing particularly on literature from HICs will be given. Following an examination of the rational or linear model, the chapter then reviews the influential work of Carol Weiss focusing on her models of research utilisation—giving particular attention to her account of the enlightenment and political models. A discussion of more recent theoretical works that attempt to model the relationship between evidence and policy, focusing in particular on Stevens’ (2007) evolutionary model, will also be given to facilitate analyses in the discussion chapter of the thesis.

Therefore, this chapter will define key terms of analytical relevance to the thesis; examine the role of evidence in HIV prevention policy development; and examine the analytical utility of existing evidence/policy theoretical models, in particular Stevens’ (2007) evolutionary model, to facilitate elements of the discussion presented within this thesis.

## 2.2 Defining evidence, evidence hierarchies and the rise of evidence-based policymaking

When attempting to answer ‘what is evidence?’ we must appreciate that this question is, in part, a philosophical one grounded in epistemological and ontological theory about how we relate to the world in terms of the genesis, interpretation and evaluation of information and knowledge (Dobrow et al: 2004: pp. 208). The question of defining evidence is also more practical as evidence is firmly embedded within the process of decision-making and can be used to explicate support and to justify the decisions that we make (Dobrow et al: 2004: pp. 208). Importantly, the philosophical and practical characteristics of evidence support two distinct orientations as to what constitutes evidence itself, reflecting different relationships between evidence and context: a philosophical-normative orientation and a practical-operational orientation (Dobrow et al: 2004: pp. 208).

A philosophical-normative orientation towards what constitutes evidence is unimpeded by context—addressing what sources of evidence would be the most ideal for supporting a decision. This orientation argues that evidence itself has inherent value with the ability to provide veridical justification for decisions (Dobrow et al: 2004: pp. 208). The philosophical-normative orientation focuses on the attributes of evidence itself, for example its validity and reliability, in order to establish the credibility of particular types of evidentiary sources for legitimising decisions (Dobrow et al: 2004: pp. 208). This orientation frames evidence and context as mutually exclusive—neglecting the role of context in decision-making and concentrating on what ought to be viewed as evidence. Consequently, from a philosophical-normative orientation, what constitutes evidence is mainly a function of the quality of evidence itself—with the supposition being that higher quality evidence should result in higher quality decisions (Dobrow et al: 2004: pp. 208). Championing this philosophical-normative orientation, in which focus is given to the simplistic quality of evidence itself, are organisations like the Cochrane and Campbell Collaborations which attempt to develop systematic

reviews of high-quality scientific evidence for health and social policy respectively (Dobrow et al: 2004: pp. 209).

Conversely, a practical-operational orientation towards what constitutes evidence is context-based, with evidence being defined with respect to a particular decision-making context (Dobrow et al: 2004: pp. 209). This orientation argues that contextual and temporal differences strongly influence the determination of what constitutes evidence. In fact, this orientation maintains that evidence itself is not static but characterised by its provisional and emergent nature being inevitably inconclusive and incomplete (Dobrow et al: 2004: pp. 209). According to the practical-operational orientation, evidence creation is highly subjective with various perspectives generating different explanations for the same decision outcome. This orientation is more aligned with the decision-making sciences as it focuses on how a range of factors contribute towards a decision-making outcome (Dobrow et al: 2004: pp. 209). Distinct from the philosophical-normative orientation, the practical-operational orientation defines evidence less by its quality and more by its relevance and generalisability to a specific context—this orientation maintains that evidence and context are mutually inclusive (Dobrow et al: 2004: pp. 209).

In the interests of transparency, it should be noted that the author considers a practical-operational orientation towards what constitutes evidence to be more persuasive than a philosophical-normative orientation. Although a philosophical-normative orientation raises important questions about the quality and validity of evidence, it limits thinking to narrowly defined evidence constructions, while neglecting the role that context plays in impacting on what constitutes evidence itself (Dobrow et al: 2004: pp. 209).

Importantly, the political context, within which evidence is used by decision-makers operating in the policymaking process, is itself central to the movement and utilisation of evidence. This is articulated by Young (2005), who argues that the links between evidence and policy are dramatically shaped by specific political contexts, whilst also noting that the policy

process itself and the production of research are, in themselves, inherently political processes from start to finish (Young: 2005: pp. 730). The significance of context, for the utilisation of evidence within policy development, is also acknowledged by Bowen & Zwi (2006), who define the context within which evidence is used by policymakers as the setting or environment where policy is developed and implemented, incorporating historical, cultural and resource contexts. They note that the political context and the multiple forces at work within policy development, provide challenges to integrating evidence into policy and practice (Bowen & Zwi: 2006: pp. 601). It is clear that context is key when attempting to understand the manner in which evidence informs subsequent policy output, and orientations that focus on the quality of evidence itself, rather than the political context within which evidence is used, neglect the broader complexity of evidence use within distinct policymaking environments. Having examined the philosophical and practical aspects of what constitutes evidence from two competing orientations, this chapter turns now to the question of how evidence is defined and constructed within the field of public health.

Within public health, evidence is multifarious as it manifests in myriad forms and the framing of evidence by those involved within public health research is a highly subjective process as the value of evidence is often “in the eye of the beholder” (Brownson et al: 2009: pp. 177). Providing a comprehensively acceptable definition of evidence is therefore problematic, as when we talk about evidence we are simultaneously talking about the meaning attributed to knowledge construction itself—a process that is non-neutral and inextricably linked to existing power relations. These notions are particularly salient within the field of public health, as action within the discipline occurs on a terrain of contested meaning and unequal power, where different forms of knowledge struggle for dominance (Schoepf: 2004: pp. 1). Evidence can therefore be defined, valued and prioritised in a highly subjective manner by individuals from distinct disciplinary perspectives at different times in different social and decision-making contexts. Evidence is essentially a fluid social construction as all evidence is individually judged, framed and valued

through a prism of our own assumptions (Porter: 2010: pp. 11). While acknowledging that epistemological and knowledge/power debates are important to consider when attempting to define evidence, it is useful to advance a working definition of evidence and to examine the problematic notion of 'hierarchies of evidence' within public health research.

A non-specific definition of evidence is advanced by Rychetnik et al (2004) who argue, in the broadest sense, that evidence can be defined as something serving as proof or facts and testimony in support of a statement, belief or conclusion (Rychetnik et al: 2004: pp. 538). This is quite a generic definition of evidence as it is devoid of context and fails to specify what counts as evidence for whom and when. A more expansive definition of evidence is provided by Fielding & Briss (2006), who argue that evidence can originate from a plurality of sources whilst noting, somewhat simplistically, that a larger body of evidence is better than a smaller one:

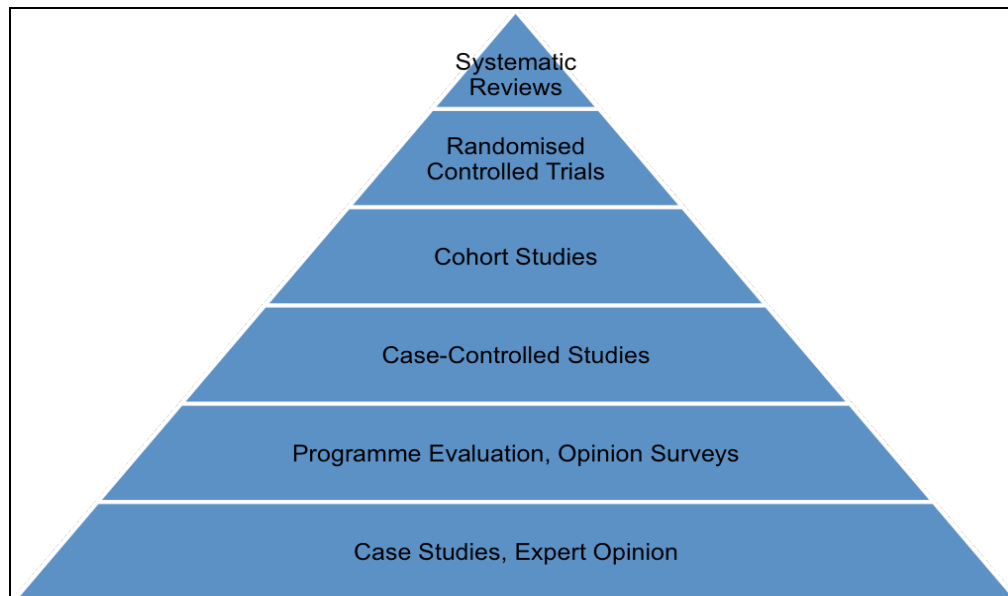
A person's hunch, an anecdotal observation, the expert opinion of a group, a formally designed and executed scientific study, or a group of studies all can constitute evidence. In general, however, scientific studies produce more reliable information than the alternatives, and multiple studies are better than single ones (Fielding & Briss: 2006: pp. 970 – 971).

A definition which considers the practical use of evidence within decision-making is advanced by Brownson et al (2009) who claim that evidence can be understood as some kind of qualitative or quantitative data, including results of program or policy evaluations, for use in making decisions or judgements (Brownson et al: 2009: pp. 177). Synthesising the definitions above, evidence can be conceptualised as various forms of data (both qualitative and quantitative) that 'come' in a multitude of forms (from personal hunches to scientific studies) which can be used to support various conclusions or beliefs. However, it is important to understand that evidence is never really a clear, accepted and bounded construct. There is also no such entity as 'the body of evidence'; rather, there are rather more and less competing reconstructions of evidence able to support almost any position (Wood et al: 1998: pp. 1735). Furthermore, evidence itself is never morally or ethically

neutral and debates over evidence reflect an underlying debate about the power to control the definition of evidence, who defines the types of materials that count as evidence, who determines the methods that generate the best forms of evidence and whose criteria are used to evaluate the quality of evidence itself (Denzin: 2009: pp. 142).

Noting that constructions of evidence are inextricably influenced by the power to control what constitutes evidence itself, it is important to explore a manifestation of the power to grade evidence via the ‘evidence hierarchy’ a linear creation underpinned by the dominant and positivist discipline of epidemiology. It is commonly acknowledged that varying degrees of confidence can be attached to different types of evidence and a well-known ‘hierarchy of evidence’, which emerged from the field of epidemiology, is frequently used within public health research to understand the relative strength of evidence itself (Evans: 2003: pp. 78). It is argued that different types of evidence can be ranked in order of their decreasing internal validity—arguing that systematic reviews and randomised controlled trials are the gold standard of evidence whereas expert opinion and editorials reside at the bottom of the hierarchy:

Table 2: ‘Hierarchy of Evidence’



(Diagram adapted from: Wilson & Mabhala: 2009: pp. 194)



This linear framing of evidence has gained both currency and legitimacy within public health research as its development emerged from the field of epidemiology—a science that has traditionally been viewed as underpinning public health (Holland et al: 2007: pp. 23). However, the ‘hierarchy of evidence’ remains a source of debate within public health research as many researchers regard it as inappropriate to rely on study design as a marker for the credibility of evidence itself (Petticrew & Roberts: 2003: pp. 527). Moreover, the concept of an evidence hierarchy is difficult to apply when attempting to appraise evidence for public health interventions, as debate remains over the very use of the term ‘evidence’ within health promotion and the role that different types of research-based information play—in particular observational and qualitative data (Petticrew & Roberts: 2003: pp. 527). Thus, McQueen (2001) contends that there is no real consensus in relation to hierarchies of evidence within public health research:

Within the general area of community research, intervention and evaluation, there is currently great debate about what constitutes knowledge within the field and what is evidence, or even whether the notion of evidence is applicable to the evaluation of interventions in communities. In summary, there is no consensus on any ‘hierarchy of evidence’ between researchers and practitioners in the field. International groups have asserted that it is premature to prioritize types of evidence in a linear hierarchy (McQueen: 2001: pp. 266).

Within public health, the social construction of quantitative evidence as more robust and more rigorous compared with qualitative evidence endures. Again, the construction of quantitative evidence as strong and qualitative evidence as weak stems from the long-standing dominance of epidemiological approaches within public health research—a discipline that places great confidence in quantitative methods to address questions of prevalence, effectiveness and causation (Jack: 2006: pp. 277). Stemming from the positioning of quantitative evidence as strong, qualitative evidence has often been constructed as weaker or less rigorous, with limited generalisability at the population-level (Jack: 2006: pp. 279). As a consequence of this framing, qualitative evidence is absent or poorly ranked within methodological hierarchies of scientific evidence (Jack: 2006: pp. 279).

Indeed, Denzin (2009) maintains that within the evidence-based community qualitative research does not count as research unless it is embedded within a randomised control trial design (Denzin: 2009: pp. 140). The effective marginalisation of qualitative evidence within much public health research is problematic as the field of health promotion, at the population-level, cuts across various sectors and disciplines (McQueen: 2001: pp. 262). Indeed, public health prides itself on being eclectic and multi-disciplinary with many of its principal activities relating to advocacy, partnerships and coalition building—areas considered to be more of an art than a science (McQueen: 2001: pp. 262 – 263). It therefore seems problematic to subscribe to the existing rules of evidence which are often based upon the underlying positivist logic of epidemiology within public health research (McQueen: 2001: pp. 266).

### *2.2.1 Examining evidence-based medicine, the establishment of evidence-based policymaking and the GRADE process for evaluating evidence*

Having defined evidence and made clear that its linear grading via the ‘evidence hierarchy’ reflects the established dominance of epidemiological and quantitative approaches within the field of public health, the chapter now examines the growth and establishment of evidence-based policymaking (EBPM). However, to provide a full account of the development of EBPM it is first required to describe its academic precursor, namely the evidence-based medicine (EBM) movement the development of which can be traced back to the early-1990s.

The EBM movement was spearheaded by epidemiologists Sackett & Guyatt in 1992 within McMaster University in Canada (Beague: 2009: pp. 1540). EBM came to fruition in an attempt to make the approach to medical practice more scientific and academically rigorous through the systematic critical appraisal of medical knowledge and by 1993 international enthusiasm for EBM coalesced with the creation of the Cochrane Collaboration which, as described above, attempts to improve decision-making by conducting

systematic reviews of the effects of healthcare interventions (Beague: 2009: pp. 1540). The arrival of EBM was highly significant described by Hitt (2001) as a revolution in the practice of medicine with its development resulting in the adoption of evidence-based approaches in multiple disciplinary fields including nursing, dentistry, occupational therapy, psychotherapy and ethics (Kohatsu et al: 2004: pp. 417). The establishment of EBM also had a marked conceptual influence in other non-clinical arenas, including education, public policy and public health (Behague: 2009: pp. 1540). Significantly, the development of EBM led to the subsequent development of EBPM which will now be defined and problematised.

According to Cookson (2005), EBPM should be understood as a set of rules and institutional arrangements to promote a transparent and balanced use of evidence in public policymaking (Cookson: 2005: pp. 118). Sutcliffe & Court (2005) maintain that EBPM can be defined as a discourse or set of methods which informs the policy process rather than attempting to determine the eventual ambitions of policy. It supports a more rigorous, rational and systematic approach to policymaking, noting that the pursuit of EBPM is premised upon the idea that policy decisions should be better informed by available evidence which should include rational analysis. It is argued that policy which is based upon systematic evidence is seen to produce better policy outcomes (Sutcliffe & Court: 2005: iii). EBPM has also been defined as an approach which permits individuals to make well-informed decisions about projects, programmes and policies by putting the best available evidence at the heart of policy development and implementation (Davies et al: 2000: pp. 11). As is emerging, EBPM attempts to promote a more rigorous and rational approach to policymaking acknowledging that policy development (and policy decisions) should be based upon high-quality evidence as this, it is assumed, will produce better policy outcomes.

An example of the application of the evidence-based approach in health policy is the Grades of Recommendation, Assessment, Development, and Evaluation (GRADE) process. This process attempts to incorporate a formalised method to rate the quality of scientific evidence in order to

produce guidelines and recommendations that are as evidence-based as possible (Dijkers: 2013: pp. 1). Deriving from clinical science, the GRADE approach has been adopted by multiple national and international organisations and represents a systematic and transparent framework for evidence-based guideline development (Guyatt et al: 2011: pp. 380). The GRADE approach, similar to the hierarchy of evidence outlined above, operates by ranking randomised control trials as high-quality evidence and observational studies as low-quality evidence. However, it is posited that the GRADE approach is much more than an actual rating system as it offers a structured process to present evidence summaries for systematic reviews and guidelines for carrying out the steps involved in developing recommendations (Dijkers: 2013: pp. 2). Since its formal development by the GRADE working group in 2000, agencies involved with global public health have utilised GRADE as it is an internationally recognised framework for assessing the quality of a body of evidence which can be used to derive the strength of potential evidence-informed recommendations (Burford et al: 2012: pp. 631). Indeed, the vast majority of specific GRADE applications in the field of global public health have occurred within the WHO, where the utilisation of GRADE has been mandatory since January 1<sup>st</sup> 2009 (Rehfuess & Akl: 2013: pp. 9).

While the GRADE approach has successfully provided guidance for rating the quality of evidence and grading the strength of recommendations in health care and clinical science (Guyatt et al: 2011: pp. 380), its application within the field of public health and by experts operating within international organisations has not been straightforward. Indeed, the application of the GRADE approach by experts in the field of public health has faced a range of challenges: the complexity of public health interventions, the ability to discriminate between different kinds of observational studies, and the use of non-epidemiological evidence in the public health field (Rehfuess & Akl: 2013: pp. 1). Significantly, the GRADE approach 'ranks' non-epidemiological evidence as very low-quality. As the assessment of the effectiveness of public health interventions frequently relies on sources of evidence *outside of* epidemiology, the application of

GRADE can be challenging due to differences between the relative ‘strength’ of clinical and public health sources of evidence (Rehfuess & Akl: 2013: pp. 8). Importantly, evidence-based public health guidance frequently relies on sources of evidence beyond the traditional hierarchy of epidemiological study design. By virtue of the public health field being multidisciplinary, the GRADE approach does not always offer a comprehensive framework for appraising, and integrating, contextualised evidence generated by disciplines other than epidemiology (Rehfuess & Akl: 2013: pp. 10).

The field of public health has also been influenced by the growth, and establishment of, evidence-based approaches leading to the creation of evidence-based public health (EBPH) and the advancement of evidence-based global health policymaking—each of which will now be defined. EBPH can be defined as a public health endeavour in which there is an explicit, informed and judicious use of evidence that has been derived from any of a selection of science and social science research and evaluation methods (Rychetnik et al: 2004: pp. 538). Brownson (1999) contends that EBPH can be understood as the development, implementation and evaluation of effective policies and programs in public health via the application of principles of scientific reasoning, including the systematic use of data and information systems and the appropriate use of program planning models (Brownson et al: 1999: pp. 87). A more population-based definition is posited by Kohatsu et al (2004), who maintain that EBPH is the process of assimilating science-based interventions with community preferences in order to improve the health of populations (Kohatsu et al: 2004: pp. 418). At the global level, Yamey & Feachem (2011) define evidence-based global health policymaking as a practice which attempts to enhance global health outcomes by urging policymakers to ground their policies on the best available evidence, rather than on the basis of whim, opinion or political popularity (Yamey & Feachem: 2011: pp. 97). It is clear from the definitions above that EBPM and evidence-based global health are explicitly concerned with the use and application of scientific data, and scientific reasoning, by using evidence from a range of sources in an attempt to enhance population health in various contexts.

However, EBPM and the purported adoption of evidence-based approaches in multiple disciplinary fields has been criticised. Significantly, EBPM is premised upon strong normative assumptions pertaining to the logical utilisation of evidence by actors who are believed to function in a comprehensively rational manner (Cairney: 2014: pp. 1). While EBPM has gradually established itself in multiple policymaking environments, becoming both an aspiration and catch-cry of governments in recent years (Botterhill & Hindmoor: 2012: pp. 367), this form of policymaking is reminiscent of 1950s rationalist understandings of policymaking where the 'best' information about 'what works' moves within the policymaking process in a deterministic and unproblematic manner. It is reasoned by Cairney (2014), that EBPM should be understood as a vague and aspirational term. Indeed, it is maintained that EBPM should be conceptualised as an idealised form of policymaking as actors who operate within the process of policymaking, make their choices based on limited information and ambiguity within complex policy environments (Cairney: 2014: pp. 1). Importantly, the actual process of policymaking is both uncertain and inherently messy and while research may deliver the latest scientific evidence, it is not always translated effectively into policy (Botterhill & Hindmoor: 2012: pp. 367). Thus, the rationalist and normative assumptions of EBPM should be viewed with caution as evidence rarely informs policy in a direct and unproblematic manner.

### *2.2.2 Examining policy, the policymaking process and policy networks*

Similar to evidence there is no universally accepted definition of policy (Cariney: 2012: pp. 23; Cairney: 2015: pp. 1; Torjman: 2005: pp. 1). Indeed, policy is widely acknowledged as a complicated term to define, however, our attempts to give it meaning are important to discuss (Cairney: 2015: pp. 1). At a very rudimentary level, policy can be understood as a general term used to describe a plan of action or formal decision to achieve a particular goal (Richards & Smith: 2002: pp. 1). Policy can therefore be understood as a guide to action to change what would otherwise occur, a decision about the

commitment to certain areas of concern with policy itself setting priorities and guiding resource allocation (Milio: 2001: pp. 622).

However, these understandings of policy overlook the significance of understanding policy in terms of non-decision-making as well as decision-making (Vital: 2013: pp. 26). Vital (2013) notes that an absence of policy can be understood as a distinct policy position in and of itself, and - in some cases - the study of issues that fail to be reflected in active policy debates may be more enlightening than a focus on decisions that have been made (Vital: 2013: pp. 26). This notion aligns with Dye's definition of public policy as "whatever governments choose to do or not to do" (Dye: 1972: pp. 3). Cairney (2012) argues that a working definition of policy can be advanced as "the sum of government action, from signals of intent to the final outcomes" (Cairney: 2012: pp. 24 – 25). However, there are some important caveats to this working definition of policy namely:

(a) it is problematic to conflate what people say they will do with what they actually do; (b) a policy outcome can be very different from the intention; (c) policy is made routinely through cooperation between elected and unelected policymakers and actors with no formal role in the process; (d) policymaking is also about the power not to do something (Cairney: 2012: pp. 24 – 25).

Policy is therefore an inherently problematic term to define, however, it can be reasoned that policy should be understood as comprising of courses of action and inaction that can be made by state or non-state actors, to achieve some desired objective. An additional notion of analytical relevance to this research project – and more broadly the field of policy analysis – is the policymaking process which will now be defined and examined. According to Parsons (1995), the policymaking process can be defined as "how problems are defined, agendas set, policy formulated, decisions made and policy evaluated and implemented" (Parsons: 1995: pp. 16). Expanding upon the definition advanced by Parsons (1995), the policymaking process can be understood as comprising of five key stages: problem identification and agenda setting, policy formation, policy adoption, policy implementation and policy evaluation each of which will now be examined.

Problem identification and agenda setting relates to the manner in which policy problems are defined and how the policy agenda is set. In this stage of the policymaking process it is contended that public problems will only reach the policy agenda when they are converted into political issues (usually occurring when interests groups demand government action on a specific problem) (WHO: 2005: pp. 3). Policy formulation is the stage in which policies are formulated or adapted. Importantly, policies are the products of the political context within which they are developed. Therefore, it is useful to conceptualise policy formation as a social and political process in order to understand how policies are actually formulated (WHO: 2005: pp. 4). Policy adoption is the stage in which policies are enacted or brought into force by actors involved with policy development and, more broadly, by state legislation. The implementation of policy relates to the mechanisms and actions in which policies are brought into practice, that is, where what is written in pieces of legislation or policy documentation are translated into reality. In this stage of the policymaking process the content of policy and its impact on those affected can be substantially modified or even negated (WHO: 2005: pp. 4). The final stage of the policymaking process is policy evaluation which includes the analysis, monitoring, criticism and assessment of existing or proposed policies. This includes the critical appraisal of policy content, its implementation and its effects, with policy evaluation aiming to help both policymakers and governments to implement policy in an efficient and effective manner (WHO: 2005: pp. 4). Having defined and examined the policymaking process, it is now required to examine another key notion of analytical relevance to this research project and the broader field of policy analysis, namely, policy networks.

According to Compston (2009), policy networks in their most rudimentary sense refer to a set of political actors outside and inside government who are involved in, or take an interest in, the creation of public policy—and/or the relations between these actors (Compston: 2009: pp. 7). A core feature of policy networks is the notion that the relationships between network members are based on resource interdependencies, with actors wanting something from one or more other actors, whilst being prepared to exchange



something of their own in order to get it (Compston: 2009: pp. 7). Buse et al (2012) echo the notions above, defining policy networks as a:

Generic term for interdependent organizations involved in an area of policy that exchange resources and bargain to varying degrees to attain their specific goals (Buse et al: 2012: pp. 106).

While the conceptualisation and definition of policy networks varies considerably between disciplines, Börzel (1998) maintains that they share common attributes including:

A set of relatively stable relationships which are of non-hierarchical and interdependent nature linking a variety of actors, who share common interests with regard to a policy and who exchange resources to pursue these shared interests acknowledging that cooperation is the best way to achieve common goals (Börzel: 1998: pp. 254).

However, it is important to appreciate that policy networks are actually political structures as the relationships within them prescribe the issues which are discussed and how they are dealt with; have sets of rules; define the roles which actors play within networks; and contain organisational imperatives, so that, at least, there is a significant pressure to maintain the policy network itself (Marsh & Smith: 2000: pp. 5). Policy networks also contribute towards the institutionalisation of beliefs, values, cultures and particular forms of behaviour. They shape actors' attitudes while helping to routinize actions within the broader process of policymaking (Marsh & Smith: 2000: pp. 6). It is additionally reasoned by Marsh & Smith (2000) that policy networks help to simplify the policy process by limiting action, problems and solutions, with policy networks themselves helping to define roles and responses (Marsh & Smith: 2000: pp. 6). In doing this, policy networks are not neutral entities and comparable to other political institutions and processes, they both reflect past distributions of power and conflicts and shape present political outcomes (Marsh & Smith: 2000: pp. 6). Importantly, the rules of the game within specific policy networks also constrain who is included in the network and how participants act within them.

Policy networks can equally limit forms of behaviour which are unacceptable and by defining the sort of behaviour that is acceptable within the networks themselves, they can privilege certain alternative outcomes (Marsh & Smith: 2000: pp. 6). It is reasoned that individual actors, who do not abide by the normalised rules within distinct policy networks, are likely to be excluded as policy networks, like other organisations, are the sum of previous policy decisions and outcomes and this is likely to privilege certain alternative policy options (Marsh & Smith: 2000: pp. 6).

### 2.3 Theorising the relationship between evidence and policy within high-income countries

There is a well-established corpus of theoretical literature that has attempted to model the relationship between evidence and policy and much of this literature has been generated within HIC contexts. While this research project is interested in examining contested explanations for the Ugandan HIV prevalence decline of the 1990s and HIV prevention policy development pertaining to sub-Saharan and global level policymaking contexts, it is first useful to examine existing theoretical models that have attempted to problematise the relationship between evidence and policy within HICs. Such examination is required as the theoretical literature attempting to model the relationship between evidence and policy pertaining to LICs, especially within sub-Saharan Africa, is underdeveloped. It is therefore necessary to retreat temporarily to theoretical literature from HIC contexts and to consider its broader analytical utility in facilitating elements of the discussion within this thesis. The sub-sections below examine four theoretical frameworks that have attempted to model the relationship between evidence and policy, namely: the linear model, the enlightenment model, the political model and Stevens' (2007) evolutionary model.

### *2.3.1 The linear model*

The linear or rational model assumes a direct link between the production of evidence and subsequent policy development. It assumes that evidence is mediated by actors operating within the policymaking process in a rational and sequential manner. The model is based on the supposition that because knowledge exists, it will consequently come to be utilised in policymaking (Monaghan: 2011: pp. 136). According to the linear model, actors operating within the policymaking process merely need to present their evidence in a convincing manner when policy decisions are being made, and if they are convincing enough, their evidence will be taken into account, and will from then on be incorporated into subsequent policy output (Overseas Development Institute: 2012).

As noted by Monaghan (2011), the linear model can be read as an amalgamation of Weiss' (1979) knowledge-driven and problem-solving models of research utilisation in which research findings are applied to policymaking in a deterministic manner (Monaghan: 2011: pp. 136). According to Weiss' knowledge-driven model, research findings provide the required pressure for policy to develop in line with the production of new knowledge. In this model, it is reasoned that basic research highlights an opportunity for policy to develop, applied research is then undertaken to test and define these findings, relevant technologies are then developed, and finally, application occurs. The model is therefore premised on the simple assumption that because novel information exists it will then be utilised in subsequent policy development (Monaghan: 2011: pp. 136).

Additionally premised upon a linear, or sequenced-based logic, is Weiss' (1979) problem-solving model which maintains that research is used to fill gaps in knowledge where particular policy problems have arisen (Monaghan: 2011: pp. 136). While premised on a linear logic, like the knowledge-driven model, the steps by which evidence informs policy are different (Weiss: 1979: pp. 427). In this model decisions drive the application

of research. A predefined problem exists and a decision has to be made, understandings of information maybe lacking to create a solution to the problem and research information provides the missing knowledge—with the gap filled with knowledge a decision is reached (Weiss: 1979: pp. 427). According to Weiss (1979), the problem-solving model is based on the sense that there is a consensus of goals amongst policymakers and researchers (Weiss: 1979: pp. 427). As policymakers and researchers agree on desired goals, the main contribution of social scientific research is to identify and select the appropriate means to reach the intended policy goal (Weiss: 1979: pp. 427). According to the two models advanced by Weiss, decision-makers have clearly defined ideas about their intended policy goals and evidence is used to fill existing knowledge gaps and to clarify their choices in an unproblematic manner.

However the linear model, and its assumption that evidence will inform subsequent policy output in a sequential manner, has been subject to extensive criticism throughout the past thirty years (Crewe & Young: 2002: pp. 2). Indeed, the linear model should be read as representing a zero-sum and outmoded understanding of the relationship between evidence and policy, as the idea that evidence informs policy in a straightforward or deterministic manner is anachronistic. Rationalist understandings of evidence utilisation tended to be popular in the age of logical positivism, and worked with Lasswell's stages heuristic model of the policymaking process, where evidence flowed through the ordered phases of the policymaking process (namely the agenda-setting, formulation, legitimation, implementation and evaluations phases) in a linear manner. However, the linear model fails to capture the complex and multidirectional nature of evidence utilisation within policymaking and it must be stated that the relationship between evidence and policy is not a directional one. Appropriately, the linear model has been subject to criticism owing to its static view of the policymaking process in which evidence is directly linked to policy (Monaghan: 2009: pp. 7). It is well-established that policymaking is "rarely characterised by rational decisions made on the basis of the best information" (Young et al: 2002: pp. 218) and the idea that evidence will

automatically translate *into* policy is too simplistic—therefore an examination of more sophisticated frameworks is required.

### *2.3.2 The enlightenment model*

A more sophisticated framework that attempts to model the relationship between evidence and policy is Weiss' (1979) enlightenment model which makes reference to the arbitrary manner in which evidence can enter the policymaking arena. It is argued by Weiss (1979) that the most frequent way in which evidence enters the policymaking arena is through the enlightenment process—which represents a more sophisticated explanation of the evidence and policy connection (Monaghan: 2011: pp. 138). According to the precepts of the enlightenment model, it is not the results of a single study, or a body of studies, that directly influence policy—rather it is the theoretical perspectives and concepts that social scientific research has engendered which permeate the policymaking process itself (Weiss: 1979: pp. 429). This model acknowledges that evidence percolates through the policymaking process and the percolation of evidence shapes the manner in which people think about particular social issues via a process of indirect diffusion (Weiss: 1979: pp. 429). Usefully, the enlightenment model is based upon a dynamic view of the policymaking process and it widens the platform upon which the evidence and policy relationship can operate (Monaghan: 2009: pp. 7).

According to the principles of the enlightenment model, there is no underlying assumption that decision-makers actively seek out evidence when faced with a specific policy issue or even that they are aware of, or receptive to, specific research conclusions (Weiss: 1979: pp. 429). It is asserted by Weiss that evidence “diffuses circuitously through manifold channels” (Weiss: 1979: pp. 429) and it is noted that policymakers will rarely be able to cite the findings of particular studies that influenced their decisions. However, they will possess an understanding that evidence has given them a backdrop of ideas that has had important consequences (Weiss: 1979: pp. 429).

– 430). Unlike Weiss' problem-solving and knowledge-driven models, the enlightenment model does not assume that research results must be compatible with decision-makers' goals and values. It is reasoned that evidence that challenges existing principles can work its way into official consciousness and with the help of dissident undergrounds it is possible to overturn established values and patterns of thought (Weiss: 1979: pp. 430). In actuality, in the enlightenment model evidence generates the conceptual tools for policymakers to facilitate their decision-making and the process of cumulating research and information over time serves to sensitise policymakers to new issues (Monaghan: 2011: pp. 138).

The process of enlightenment should be understood as a two-way process—in one direction it generates the awareness of decision-makers to specific issues, which can help set the agenda and the construction of certain problems as requiring solutions. Whereas, in the other direction, research can turn what were formerly pressing problems into lesser policy issues which can change the boundaries over where solutions are sought (Monaghan: 2011: pp. 138). While the enlightenment model acknowledges that the policymaking process is dynamic and that evidence percolates into policy over time via a range of channels, it is noted that the model is conceptually deficient. Significantly, the filtration mechanism by which certain kinds of evidence are siphoned out of the policymaking process is absent, and there is an underlying assumption that all kinds of evidence have an equal chance of being utilised in decision-making (Monaghan: 2009: pp. 7).

### *2.3.3 The political model*

Weiss' (1979) political model is characterised by the selective use of evidence by decision-makers to satisfy their short-term interests (Weiss: 1979: pp. 7). According to the political model a constellation of competing interests around a particular policy issue coalesce and predetermine the positions that decision-makers take (Weiss: 1979: pp. 429). It is argued for reasons of interest, intellect or ideology that decision-makers are not likely to be

receptive towards new evidence that emerges from social scientific research (Weiss: 1979: pp. 429). Indeed, it is reasoned that evidence does not have any bearing on predetermined policy positions and evidence is used by decision-makers as ammunition to convince waverers, to neutralise supporters or to bolster supporters (Weiss: 1979: pp. 429). It is maintained by Weiss (1979) that the political use of evidence by decision-makers operating within the broader policymaking process can take place for three key reasons: agency justification, self-serving purposes and personal aggrandizement (Weiss: 1979: pp. 429). The political model therefore highlights the important influence of individual agency and its sway on the relationship between evidence and policy.

According to the precepts of the political model, when new evidence is developed it is argued that it will have a negligible influence on decision-makers' predefined policy positions with evidence therefore serving a legitimising or justificatory function (Monaghan: 2011: pp. 139). The political model of research utilisation is a more sophisticated framework which better describes the relationship between evidence and policy, and it aligns with Weiss' perceptive summation of the policymaking process itself which is viewed as an inherently political process, with the basic aim of reconciling interests in order to negotiate a consensus, not implementing logic and truth (Weiss: 1977: pp. 533).

While the political model as distinct from the linear and enlightenment models starts to "descend the ladder of abstraction" (Monaghan: 2011: pp. 140) to consider how evidence is, or is not, selected in policy decision-making (Monaghan: 2011: pp. 140) it too possesses conceptual limitations. It is reasoned that despite its acknowledgement of political imperatives upon the use of evidence in policy formation, the underlying logic of the political model is still linear (Monaghan: 2011: pp. 140). It is also contended that the political model offers a short-term and static understanding of the policymaking process, screening out the unintentional and serendipitous ways that evidence can come to be utilised in policymaking (Monaghan: 2011: pp. 140). It is even contended that the political model provides a

restrictively narrow view of the evidence and policy connection, as if it was somehow deterministic which therefore neglects the unstable nature of policy development itself (Monaghan: 2011: pp. 14). It is argued by Monaghan (2009) that the models outlined above (namely the linear, enlightenment and political models) function at too high a level of abstraction and that they provide inadequate grounds to conceptualise the relationship between evidence and policy—especially within heavily politicised policy areas (Monaghan: 2009: pp. 1). It is therefore warranted to examine a more contemporary framework that pays attention to the specific mechanisms through which evidence informs, or fail to inform, subsequent policy development—in particular Stevens’ (2007) evolutionary model.

#### *2.3.4 The evolutionary model*

Stevens’ (2007) evolutionary model examines bias in the use of evidence in policy development, arguing that existing models of the relationship between evidence and policy ignore the tendency for attention to be given to evidence helpful to the interests of powerful social groups (Stevens: 2007: pp. 25). It is asserted, without the need for conspiracy or irrationality on the part of policymakers, that an evolutionary analogy can be used to explain how bias arises and its influence upon the use of evidence in policy development (Stevens: 2007: pp. 25). It is argued that an evolutionary analogy can be used to go beyond the conceptual limitations of Weiss’ political model, by helping to explain how evidence can be used selectively to advance the interests of powerful social groups, without relying on the deliberate involvement of policymakers—seeing social structures and political tactics as important in supporting selection in the use of evidence (Stevens: 2007: pp. 28 – 29). Using an evolutionary analogy, influenced by notions of social Darwinism, it is reasoned that:

A variety of ideas come from evidence and compete for attention in policy, as genes arise and compete for survival. The ideas may be facts, findings or recommendations that have been produced by academics, journalists, think tanks, pressure groups or others.



Some of these ideas fit with the interests of powerful groups and some do not. Ideas that do fit will find powerful supporters. Others will not. Those ideas that fit will therefore have groups and individuals that can carry them into policy, as would a gene be reproduced if it finds a place in organisms that survive. The ideas that do not fit will tend not to be picked up by the people who have the power to translate them into policy. The evolutionary advantage leads to the survival of the ideas that fit (Stevens: 2007: pp. 28).

It is argued by Stevens (2007) that the advantage of this biological analogy is that it highlights the biased use of evidence without relying on policymakers to be irrational, or the ability of powerful social groups to implement coordinated campaigns to ignore obstructive research (Stevens: 2007: pp. 28). Reflecting on the information above, it can be appreciated that the pattern of evidence selection is based upon evolutionary social theory and that evidence comes to inform policy when it aligns with the ideas of those in positions of power (Monaghan: 2009: pp. 8). The model also equates evidence to ideas (the facts, recommendations and findings produced by a plurality of actors). It is reasoned by Monaghan (2009) that by focusing the analysis at the level of ideas, a wider understanding of evidence can be ascertained. Unlike the models outlined above (namely the linear, enlightenment and political models) the evolutionary model gives significant analytical attention to carefully defined mechanisms of selection and the influence of power within the broader policymaking process. It is reasoned that individuals functioning within the policymaking process have the power to pick up bits of evidence that confer advantage to ideas that suit the interests of powerful groups—and similar to biological evolution the process of evidence selection is messy, complicated and sometimes brutal (Stevens: 2007: pp. 28). Usefully, Stevens (2007) advances five mechanisms of evidence selection, namely: trawling, farming, repetition, flak and strain and their influence upon the use of evidence within policy development—each of these mechanisms of selection will now be examined.

Trawling relates to policymakers, political parties, businesses and pressure groups fishing for evidence, hauling in the bits that suit their needs, and throwing back those bits that do not (Stevens: 2007: pp. 28). Farming may

also occur which relates to actors commissioning research but only disseminating and using parts of it that meet the criteria set for the flavour and look of the evidence generated (Stevens: 2007: pp. 28). Repetition, it is argued, is a useful tool to ensure that attention is given to useful evidence. It is claimed that actors, who possess a voice within the policy process, can repeatedly refer to bits of evidence, that may be ripped out of context and based upon methodologically suspect research. However, via repetition, such evidence can then become part of the accepted body of knowledge within a specific policy area (Stevens: 2007: pp. 28). It is also maintained that flak can be used by powerful social groups to silence, discredit or attack evidence that comes into the public arena. Strain may also be implemented by powerful social groups upon organisations and individuals that produce and advocate unhelpful evidence, who may find that doing so is not conducive to organisational survival or to a successful career (Stevens: 2007: pp. 28).

Power is key to the implementation of the aforesaid mechanisms, with those groups with the most power in society being able to apply these mechanisms to draw attention towards evidence that suits them and to encourage the ignorance of evidence that does not (Stevens: 2007: pp. 29). However, it is reasoned by Stevens (2007) that this does not mean that powerful social groups dominate the use of evidence entirely. Weaker social groups including environmental pressure groups and trade unions may also attempt to make these mechanisms of selection work for them. However, they have reduced access to the sources of research and they are less able to impose their own interpretations of research evidence on a wider public. It is also contended that weaker social groups have less opportunity to farm or trawl evidence, to repeat favourable evidence, to create flak, or to impose strain on those who generate and disseminate unhelpful research (Stevens: 2007: pp. 29). Usefully, Stevens (2007) contends that the selective use of evidence maybe more likely to take place in more contentious policy arenas which, according to his analysis, included the fields of drug, asylum, alcohol and environmental policy. However, Stevens (2007) realises that his evolutionary model requires more testing in other policy fields before it can be advanced

as a reliable description of the evidence/policy connection (Stevens: 2007: pp. 32). Realising that the selective use of evidence is more likely to occur in contentious policy areas, and the need to test the evolutionary model in additional policy fields, part of the discussion chapter will examine the analytical capacity of Stevens' (2007) evolutionary model in relation to the empirical findings that emerge from this study.

The primary reason for using Stevens' (2007) evolutionary model within parts of the forthcoming discussion chapter relates to the useful mechanisms of evidence selection (trawling, farming, repetition, flak and strain) and the wider influence of power upon the process of evidence utilisation and subsequent policy development. The secondary reason relates to the recognised influence of politics within the field of HIV/AIDS policy and the contested nature of the Ugandan HIV decline of the early to mid-1990s. The politics surrounding the Ugandan HIV decline, and the acknowledged political nature of HIV/AIDS policymaking domains, are relevant reasons which necessitate the use of an evidence/policy theoretical model that can account for the selective use of evidence within policy development. Having introduced Stevens' (2007) evolutionary model, and examined its analytical potential in facilitating elements of the discussion chapter, it is now required to provide a concise discussion about the use of evidence within policymaking and to elucidate key issues that influence the utilisation of evidence within the public health field.

### *2.3.5 Discussion on the use of evidence within the field of public health*

This chapter has so far highlighted that the use of evidence within the broader policymaking process is inherently complex with political, ideological and economic factors influencing the relationship between evidence and policy itself. It has also been ascertained that the use of evidence, within the field of public health, is complicated by the socially constructed nature of evidence and the idea that different kinds of evidence struggle to control action within the discipline. However, there are two

additional problems that need to be considered in relation to the use of evidence within the field public health, namely, the complex process of evidence use within the discipline and the influence of individual agency upon the utilisation of evidence itself.

First, the use of evidence within public health should be understood as an imperfect process. While it would be advantageous for public health practitioners to incorporate scientific evidence when developing policies and making decisions, in reality, decisions are frequently based on short-term demands and policies are often developed around anecdotal evidence (Brownson et al: 1999: pp. 87). Moreover, policymakers within the public health field, when left to their own devices, can tend to make a highly selective use of evidence due to political incentives and psychological biases towards over-confidence in one's own judgement (Cookson: 2005: pp. 119). While there is a commonplace assumption that decision-makers involved within public health will use the best available evidence to support the decisions they make, the best available evidence may not be good evidence. Furthermore, evidence can be biased, willingly or unintentionally, or even fabricated (Banta: 2003: pp. 569) and it is key to note that evidence use is based upon a combination of professional judgement, common sense and, at times, convincing evidence within public health is mainly a matter of presentation and rhetoric (Banta: 2003: pp. 569). The issue of the use of evidence within public health is therefore exceedingly complex, and as Banta (2003) argues, no existing model is adequate to the task of answering all the important questions concerning the use of evidence within the public health field (Banta: 2003: pp. 570). It is therefore not appropriate to subscribe to the precepts of existing theoretical frameworks that have attempted to model the relationship between evidence and policy in their totality. However, it is important to use existing models, like Stevens' (2007) evolutionary model, in an instrumental manner and to adapt aspects of existing models to new policymaking contexts and emerging research findings.

A second problem which needs to be discussed when thinking about the function of evidence within the field of public health is the influence of

individual agency. Importantly, individuals involved with the mediation of evidence and the development of policy often make decisions in light of uncertainty and their decisions are not always done on a scientific basis (Choi et al: 2005: pp. 636). Scientific evidence may also conflict with the respective beliefs and values of policymakers and those involved with policy development may use evidence in the battle to control problem definition and policy solutions (Choi et al: 2005: pp. 636). Individual policymakers thus frequently search for evidence to support their own claims, which often results in systematic bias occurring in the way that policymakers look for and use data (Choi et al: 2005: pp. 633). Evidence may also fail to be used in policy development by individuals as new forms of evidence can be perceived as threatening to existing power relationships or entrenched vested interests, rather than because evidence is flawed or insufficiently robust (Hunter: 2009: pp. 583).

It is also important to appreciate that evidence is only one of many considerations that lead to the development of subsequent policy output. It is often neglected that the development of policy is based on individual values and human emotions. Policy development, and the use of evidence to support policy change, is often shaped by the emotive actions of individual decision-makers who may use evidence in a strategic and political manner. The importance of individual agency upon the use of evidence within policymaking is acknowledged by Bowen & Zwi (2006). They assert that individual decision-makers are key in deciding about the use of evidence within policy development, as it is individuals who can decide whether to accept or reject something new (Bowen & Zwi: 2006: pp. 602). However, individual decisions are shaped by a range of factors including personal qualities and capacities such as beliefs and values, knowledge and leadership skills, broader organisational support, partnership links and networking (Bowen & Zwi: 2006: pp. 602). Importantly, the capacities and personal qualities of individual decision-makers can influence the uptake of evidence in decision-making processes and when individuals perceive evidence to be useful, compatible and comprehensible with their past experiences, it stands

a better chance of being used in policy development (Strydom et al: 2010: pp. 2).

## 2.4 Examining the role of evidence in the formulation of HIV prevention policy focusing on literature from Uganda

This section of the chapter examines literature on the role of evidence in the formulation of HIV prevention policy, giving analytical focus to literature from Uganda. This exploration is required in order to ground the thesis in an appropriate body of knowledge which will facilitate the subsequent analysis of contested explanations for the decline in HIV prevalence in Uganda, and the role of evidence in the development of global HIV prevention policy in the 1990s. Two sub-sections will be advanced within this portion of the chapter. The first locates and summarises the underlying Ugandan HIV/AIDS surveillance data sources referred to by experts and institutions in developing HIV prevention policy in the 1990s. The second describes how these data were interpreted by different groups of actors involved with national and international HIV/AIDS prevention, and key contextual factors that appeared to influence the process of evidence interpretation by those involved with HIV/AIDS prevention in the 1990s.

Before examining the interpretation and use of Ugandan HIV/AIDS surveillance data in the formulation of HIV prevention policy, it is first essential to present the underlying sources of epidemiological and sexual behavioural surveillance data that were subsequently interpreted and used to create HIV prevention policy in the 1990s. This is achieved via a review of UNAIDS/WHO best practice policy documentation, which provide formative accounts of the Ugandan HIV prevalence decline of the 1990s, and are purportedly the original sources of data used to advance the narrative of HIV decline that emerged in the early to mid-1990s. UNAIDS asserts that the original sources of data used by the Ugandan Government and international organisations to develop HIV prevention policy were a combination of: antenatal HIV seroprevalence data, behavioural data emerging from

population-based surveys of sexual behavioural change and a range of smaller-scale sociological studies (see UNAIDS: 1998a & UNAIDS: 1998b). Each of these data sources will now be outlined as their use was key to the development of subsequent Ugandan and global HIV prevention policies in the 1990s.

It is widely claimed that antenatal HIV seroprevalence data were used to demonstrate Uganda's HIV decline of the early to late 1990s. Kirungi et al (2006) assert, via an analysis of ANC seroprevalence data, that there was a peak in HIV prevalence rates somewhere between 15 – 30% in seven urban clinics in 1992 followed by a steady decline by 2002 to 5 – 12% (Kirungi et al: 2006: pp. 36). Echoing this contention is Okware et al (2005) who also noted that HIV seroprevalence among women attending urban antenatal clinics throughout Uganda declined from about 30% in 1992 to 10% in 2002 (Okware et al: 2005: pp. 625). Indeed, multiple authors acknowledge that Uganda successfully reversed a generalised, high prevalence epidemic from as high as 30% in 1992 to as low as 6% in 2000 among women attending certain urban antenatal clinics (Merson: 2006; Genius & Genius: 2005; Kirby: 2008; Okware et al: 2001; Slutkin et al: 2006; Stoneburner & Low-Beer: 2004). In 2001 the Ugandan Ministry of Health produced a report summarising the declining trends in HIV seroprevalence data from 1989 to 2000 in 15 surveillance sites:

Table 3: HIV seroprevalence rates in Uganda from 1989 - 2000

Site	1989	1990	1991	1992	1993	1994	1995	1996	1997	1998	1999	2000
Nsambya	24.5	25.0	27.8	29.5	26.6	21.8	16.8	15.4	14.6	13.4	12.3	11.8
Rubaga	-	-	27.4	29.4	24.4	16.5	20.2	15.1	14.8	14.2	10.5	10.7
Mbarara	21.8	23.8	24.3	30.2	18.1	17.3	16.6	15.0	14.5	10.9	11.3	10.0
Jinja	24.9	15.8	22.0	19.8	16.7	16.3	13.2	14.8	11.0	10.5	10.8	8.3
Tororo	-	4.1	12.8	13.2	11.3	10.2	12.5	8.2	9.5	10.5	4.5	4.7
Mbale	3.8	11.0	12.1	14.8	8.7	10.2	7.8	8.4	6.9	6.3	5.7	5.5
Kilembe	-	-	-	-	7.0	16.7	11.1	10.4	8.5	-	7.5	4.2
Soroti	-	-	-	-	9.1	-	8.7	7.7	5.3	7.7	5.0	5.0
Hoima	-	-	-	-	-	-	-	12.7	9.0	5.4	3.5	-
Arua	-	-	-	-	4.4	-	-	-	-	-	5.2	5.2
Pallisa	-	-	-	7.6	5.0	1.2	-	-	3.2		3.2	3.8
Matany	-	-	-	-	2.8	7.6	-	2.0	1.6	1.3	0.9	1.9
Kagadi	-	-	-	-	-	-	-	-	10.3	11.5	11.0	10.5
Mutolere	-	4.1	5.8	-	4.2	-	3.6	2.6	-	2.5	2.3	2.1
Moyo	-	-	-	-	5.0	-	3.1	-	-	3.2	5.2	2.7

(Ugandan Ministry of Health HIV/ AIDS Surveillance report: 2001: pp. 3).

To understand the underlying behavioural mechanisms, that could account for the aforementioned declining trends in HIV seroprevalence in Uganda, UNAIDS describes two wide-ranging population-based surveys of sexual behavioural change that were conducted in 1989 & 1995. It is asserted that there was adequate overlap between the studies to permit analytical comparison as the same population range, the same survey methodology and the same key questions on sexual behaviour were used in both surveys (UNAIDS: 1998b: pp. 9). Two geographical areas were covered in the surveys (namely urban Kampala and urban Jinja) as seroprevalence surveillance had been carried out in these locales between 1989 & 1995. In 1989 the sub-sample of the behavioural surveys that corresponded to the surveillance areas totalled 1,186 individuals and in 1995 it totalled around 1,600 (UNAIDS: 1998b: pp. 9). UNAIDS (1998) maintain that the two sub-samples



were comparable in most respects, as the specific age distribution of respondents was not majorly different between the two periods. It is also noted that the 1995 population-based survey also included questions on whether or not respondents had changed their sexual behaviour over the previous five years (UNAIDS: 1998b: pp. 9). It is posited that the analysis of sexual behavioural change data – via the comparison of the 1989 & 1995 surveys – demonstrated significant differences in sexual behaviour in almost every aspect that was investigated (UNAIDS: 1998b: pp. 9). Three key findings emerged from the analysis of the 1989 & 1995 surveys in particular: delayed age at first sex, fewer sexual relations with non-regular partners and increased condom use.

Pertaining to delayed age at first sex, it is reasoned that the proportion of females aged between 15 – 19 reporting that they had never had sexual intercourse increased from 26% to 46%. For males aged 15 – 19, the proportion increased from 31% to 56%. For the youngest age cohort, specifically 15 year olds, the proportion of boys and girls reporting that they had never had sex rose from 20% to 50% between 1989 & 1995 (UNAIDS: 1998b: pp. 9). UNAIDS additionally noted that there were declines in the number of sexual relations with non-regular partners. It is asserted that the proportion of men who reported sex outside a regular partnership in the previous year declined from 22.6% to 18.1% (also noting that the number of sexual partners tended to be fewer, with the arithmetic mean falling from 2.3 to 2.0). For females it is reported that there did not appear to be any significant change, with the proportion reporting sex with non-regular partners increasing from 6% to 8% (an increase that was not considered to be statistically significant) (UNAIDS: 1998b: pp. 10). UNAIDS also reason that between 1989 & 1995 the percentage of sexually active people claiming to use condoms increased significantly. For men, the proportion of people who declared that they had ever used a condom increased from 15% to 55% and for women from 6% to 39%. It is equally maintained that the 1995 population-based survey demonstrated that condom use tended to be higher for those who had sexual intercourse with a non-regular partner in the

previous 12 months, noting that condom use was 66% for men and 49% for women in their last sexual intercourse of risk (UNAIDS: 1998b: pp. 10).

The UNAIDS report also states that sources of data used to understand the declining trends in HIV infection in Uganda and to inform the development of subsequent HIV prevention policy, were 300 quantitative and qualitative small-scale sociological surveys (UNAIDS: 1998b: pp. 11). While UNAIDS (1998) acknowledged that these data sources did not provide directly comparable data over time, they did support the proposition that there had been a significant shift in attitudes and behaviour (UNAIDS: 1998b: pp. 11). Key findings emerging from a UNAIDS commissioned literature review which analysed the 300 surveys included: changes in age at first sex, downward trends in age at first marriage, changes in sexual relations with non-regular partners, and increased condom use (UNAIDS: 1998b: pp. 11).

UNAIDS (1998) assert that in relation to age at first sex, demographers and anthropologists recorded a lower proportions of male and female youths (aged 20 – 24) who reported first sex under the age of 19 compared with results in the late 1980s (UNAIDS: 1998b: pp. 11). Pertaining to age at first marriage, a downwards trend for the median age was observed from the 1980s and early 1990s. It is reasoned that this trend could be associated with hardship, insurgency and war – while also noting that this trend could have been due to the fear of AIDS and the desire by men for a non-infected female partner (UNAIDS: 1998b: pp. 11). It is additionally noted by UNAIDS that there was relatively little reliable quantitative evidence pertaining to sexual relations with non-regular partners. However, UNAIDS' interpretation of these data was that individuals in Uganda were increasingly being faithful to regular partners (UNAIDS: 1998b: pp. 11). Echoing the analysis from the 1989 & 1995 population-based surveys of sexual behavioural change, it was reasoned by the authors of the UNAIDS report that different studies indicated significant increases in condom use. It was noted that the proportion of sexually active people who had ever used a condom increased nationally between 1987 & 1996 from about 3% to 25% (UNAIDS: 1998b: pp. 11). Thus, via an analysis of the 1989 & 1995 population-based surveys of

sexual behavioural change (and 300 smaller-scale sociological studies) it was reported that declining trends in Ugandan HIV infection were the result of an “increase in condom use, a delay in the onset of sexual intercourse, and to a lesser extent a reduction in the number of sexual partners” (UNAIDS: 1998b: pp. 13).

## 2.5 Examining the interpretation, and use of, Ugandan behavioural surveillance data in HIV prevention policy development in the 1990s

Having presented the underlying epidemiological and behavioural data sources which gave experts and institutions formative understandings about declining trends in HIV prevalence within Uganda in the 1990s, it is now required to examine their interpretation. Specifically, this section will explore how the outlined sources of Ugandan data were divergently interpreted by actors involved with HIV prevention in the 1990s and factors that influenced the actual process of evidence interpretation itself, focusing on the role of individual beliefs and complex cognitive framing processes. This examination will also involve a discussion of the Ugandan Abstinence, Being Faithful and Condom Use (ABC) prevention approach to HIV and how advocates of the individual elements of the ABC prevention model interpreted the Ugandan HIV surveillance data in a heterogeneous fashion.

It must be noted that the interpretation of the outlined Ugandan epidemiological and behavioural data sources was inherently complex—especially during the mid-1990s. This complexity directly relates to actors involved with HIV prevention interpreting the sexual behavioural change surveillance data in both a heterogeneous and highly partisan manner. Merson (2006) contends that the complexity surrounding the interpretation of sexual behavioural change data gravitates around the relative importance given to specific components of sexual behavioural modification, namely: abstinence, partner reduction, condom promotion and their contribution to declining trends in Ugandan HIV prevalence (Merson: 2006: pp. 333).

Okuonzi & Epstein (2005) also note that the analysis of the aforementioned Ugandan sexual behavioural change data led to a highly partisan debate between advocates of condoms versus abstinence and partnership reduction in the 1990s (Okuonzi & Epstein: 2005: pp. 3). While evidence supporting the sexual behavioural change reasons that could account for declining Ugandan HIV trends, and the subsequent direction of HIV prevention policy development, are contested and far from conclusive (Kiweewa: 2008: pp. 56), two key competing interpretations emerged in the mid-1990s. Specifically, abstinence and partner reduction interpretations versus increased condom uptake interpretations.

Kiweewa (2008) argues that empirical studies provide support for the idea that abstinence and partner reduction were the primary factor in reducing HIV prevalence in Uganda. Kiweewa (2008) noted that Stoneburner & Low-Beer (2004) maintained that partnership reduction – known colloquially within Uganda as zero-grazing – was equivalent to a vaccine of 80% effectiveness (Kiweewa: 2008: pp. 56). It is additionally reported by Kiweewa (2008) that advocates of condom use advanced similarly compelling anecdotal and empirical data as proof that it was condom use and *not* abstinence and partner reduction that could account for the observed declines in HIV prevalence and incidence (Kiweewa: 2008: pp. 57). However, Kiweewa (2008) maintains that evidence pertaining to the Ugandan HIV decline is inconclusive, contending that it is virtually impossible to disaggregate the relative contribution of specific behavioural programs embedded in the ABC model to any decline in the HIV epidemic (Kiweewa: 2008: pp. 57). Merson (2006) echoes this supposition noting that while significant effort has been made to determine the precise cause of the decline in HIV prevalence in Uganda, it may never really be possible to disaggregate fully the contribution to the decrease in HIV prevalence (Merson: 2006: pp. 333). While Merson (2006) asserts that it is not possible to disaggregate the specific reasons that caused the Ugandan HIV decline, a retrospective analysis of Ugandan sexual behavioural change data which attempted to disaggregate the behavioural data and the causal reasons accounting for the Ugandan HIV decline was implemented by Kirby in 2004.

Kirby's (2004) analysis is useful to consider as it combined multiple sources of Ugandan evidence, including the data sources outlined in the previous section. It concluded that the main behaviour changes seen were a reduction in the average number of sexual partners, along with a delayed onset of sexual activity. Condom use was also noted as contributing to declining HIV trends, however this occurred later than these initial behavioural changes (Kirby: 2004: pp. 28; Parkhurst: 2012: pp. 20). Green (2006) also claims that condom use was not a central element of Uganda's early response to HIV/AIDS, especially between 1986 & 1991, noting that the debate over what happened in Uganda was reflective of divisive abstinences-versus-condoms rhetoric, which appeared more related to culture wars in the USA than to African social reality (Green et al: 2006: pp. 335).

Thus, two schools of thought emerged over the behavioural change evidence used to understand the Ugandan HIV decline, and the subsequent direction of HIV prevention policy in the 1990s, with one school contending that it was the abstinence (A) and being faithful (B) factors that could account for the success against HIV/AIDS (see Green et al: 2006; Hearst & Chen: 2004; Stoneburner & Low-Beer: 2004). The second school of thought emphasised condom use (C) and other structural factors – including poverty reduction, female empowerment and economic stability as largely responsible for the decline (Kiweewa: 2008: pp. 56). Again, advocates of the A & B elements of the ABC model maintain that various sources of evidence indicated that condom use was relatively low within Uganda in the early 1990s. For example, Hogle et al (2002) maintained that increased condom use had been relatively minor in Uganda – ranging from 1% in 1989 to 6% in 1995 and 16% in 2000 for females and from 16% in 1995 to 40% in 2000 for males. Kiweewa (2008) reasons that as most significant declines in HIV prevalence had already taken place by 1995, it is asserted that it was highly improbable that increased condom use played a significant role in the HIV decline (Kiweewa: 2008: pp. 56). Again, however, the epidemiological and sexual behavioural data – which allowed actors in the 1990s to advance formative explanations for the decline in HIV and to shape the subsequent direction of HIV prevention policy are limited.

Parkhurst (2012) even asserts that the underlying epidemiological data, used to demonstrate the decline in Ugandan HIV infection, have been based on misinterpretation with claims of Ugandan success being based upon selective pieces of data, which have been falsely presented as representative of the nation as a whole (Parkhurst: 2012: pp. 78). Therefore, it is important to acknowledge that the interpretation of Ugandan epidemiological and sexual behavioural change data was complex as various actors generated competing behavioural understandings of the Ugandan HIV decline which ultimately shaped the direction of subsequent HIV prevention policy in the 1990s. It is equally important to acknowledge that the underlying data sources, used to support the narrative of Uganda's decline and the ABC prevention model, were far from conclusive, leading certain authors to reason that it remains impossible to locate *the* definitive reason that could account for the Ugandan HIV decline.

As demonstrated above, it is clear that the interpretation of the outlined epidemiological and behavioural data sources was inherently complex, as actors involved with HIV prevention analysed the sexual behavioural change surveillance data in both a heterogeneous and highly partisan manner. Parkhurst (2012) advances an additional range of factors that appeared to influence the interpretation of Ugandan behavioural evidence and its subsequent use in the development of international HIV prevention policy. Analysing how evidence supporting the formulation of international HIV prevention policy, namely PEPFAR's ABC approach, was influenced by cognitive framing processes, it is claimed that interpretations of evidence reflected internal consistency with individual core beliefs about sexual behaviour (Parkhurst: 2012: pp. 17). Relying on theoretical literature from cognitive science and psychology, Parkhurst (2012) conducts a critical discourse analysis of interviews and textual data surrounding PEPFAR's ABC prevention approach to HIV. He explains how Ugandan evidence, which was used to justify PEPFAR's decision to use the ABC approach, was framed to develop policy responses to international HIV prevention. Interestingly, the study attempts to examine how Ugandan evidence supporting the ABC prevention approach were competitively analysed by

those involved with HIV prevention, and how the same set of Ugandan historical and epidemiological evidence was interpreted in different ways by different groups of policymakers within PEPFAR (Parkhurst: 2012: pp. 18). Parkhurst (2012) claims that various players in PEPFAR referred to particular elements of the ABC approach, how different lessons were drawn from it and how this led to competing HIV prevention policy recommendations (Parkhurst: 2012: pp. 18). It is asserted that various players within PEPFAR adopted different positions in relation to HIV prevention on the basis of analysing the same HIV evidence from Uganda and how those players (from various sides of the ABC debate) claimed that their diverging interpretations of the Ugandan HIV prevention approach were 'evidence based' whilst drawing on the HIV prevention experience of Uganda to justify their conclusions (Parkhurst: 2012: pp. 17).

The study examines how policy constructions of HIV prevention derive from competing underlying moral belief systems, the interpretive framing process based on those beliefs and their influence on evidence (Parkhurst: 2012: pp. 19). On the basis of cognitive psychological theory, it is posited that individual belief systems shape the understanding of evidence itself, as well as how pieces of evidence can be interpreted in ways consistent with one's worldview (Parkhurst: 2012: pp. 29). In this light, it is reasoned that interpretations of complex information that are most consistent with core beliefs are most likely to be developed into decisions, arguments and ideas (Parkhurst: 2012: pp. 29). It is asserted by Parkhurst (2012) that how humans deal with complexity, and manage to make sense of evidence when there are limitations in that evidence, is critical to understanding the role of evidence in HIV prevention policy formulation. Parkhurst (2012) equally maintains that cognitive psychological theories can provide a useful avenue to understand how humans negotiate complex evidence, arguing that when faced with complexity, the human mind uses simplifying heuristics and processes of association in order to understand information (Parkhurst: 2012: pp. 21). Usefully, cognitive science has explored how humans comprehend information and make decisions, especially in situations of complexity and uncertainty. It is reasoned that information is processed by, and understood

with reference to, simplifying models based on past experiences, expectations or personal beliefs (Parkhurst: 2012: pp. 19).

Importantly, understanding these issues can facilitate an analysis of how groups with contrasting belief systems interpret and use evidence differently – not just because they are seeking different policy outcomes but also because their existing beliefs will structure the cognitive frames through which new evidence is understood and applied (Parkhurst: 2012: pp. 19). It is reasoned by Parkhurst (2012) that this process can be linked to political concerns. Advancing a cognitive-political approach to the use of evidence in policy which can facilitate an understanding of the reasons behind differing portrayals of evidence in controversial policy debates (Parkhurst: 2012: pp. 19). Valuably, Parkhurst's analysis examined how various players within PEPFAR examined Ugandan evidence which supported the ABC prevention approach to HIV. However, the study demonstrated that the Ugandan sources of evidence supporting the application of the ABC approach by PEPFAR were competitively interpreted, with decision-makers aligning their own interpretations of evidence in line with their core beliefs about sexual behaviour itself. Indeed, Parkhurst's analysis demonstrated that explanatory terms and statements of justification illustrated the fundamental difference between opposed groups, stemming from their core belief systems on sexuality (Parkhurst: 2012: pp. 30).

On the basis of Parkhurst's analysis it can be posited that individuals involved with the formulation of HIV prevention policy will often use and frame evidence in a manner that is consistent with their previous beliefs, their underlying values and past experiences. Importantly, the role of evidence in relation to the development of HIV prevention policy is clearly contingent upon individual belief systems and complex cognitive framing processes, which links and interprets information to ensure consistency, or alternatively which rejects or questions information that is not consistent with past experiences and deeply held beliefs (Parkhurst: 2012: pp. 21).



Therefore, the individual framing of evidence by experts involved with HIV prevention policy development, is important to consider when understanding the process by which public health evidence comes to be developed into subsequent policy recommendations. Via the critical analysis of PEPFAR's ABC policy for HIV prevention and the function of Ugandan evidence in shaping PEPFAR's international HIV prevention policy approach, it is clear that rather than speaking for itself, sources of Ugandan evidence were defined by framing processes, with competing interpretations of the *same* evidence found to reflect internal consistency with core beliefs about sexual behaviour (Parkhurst: 2012: pp. 17). Importantly, Parkhurst's study demonstrates the analytical imperative to make explicit the complex role that individual belief systems play in shaping how evidence is used in the development of HIV prevention policy development (Parkhurst: 2012: pp. 17).

This section has examined literature on the role of evidence in the formulation of HIV prevention policy, focusing on literature from Uganda. It is beginning to emerge that the existing body of knowledge in this area highlights the complex and partisan manner in which Ugandan HIV surveillance data were interpreted and utilised by policymakers to inform the subsequent direction of HIV prevention policy in the 1990s. The reviewed literature within this section indicate that the use of evidence pertaining to the development of HIV prevention policy is contingent upon the individual agency of HIV/AIDS experts, their underlying belief systems, and complex framing processes. Importantly, these contextual influences appear to shape the interpretation and utilisation of behavioural evidence by experts involved with HIV/AIDS prevention and the respective significance attached to individual components of sexual behavioural change (namely abstinence, condom use and partnership reduction). While the studies outlined above have provided an account of the complexity surrounding the interpretation of Ugandan HIV surveillance data in HIV prevention policy development, they have not examined the contested nature of the decline in HIV prevalence in Uganda in substantive analytical detail. Equally, they have not given focused analytical attention to the political and institutional

context within which the contested sources of behavioural evidence were analysed and subsequently used to advance formative explanations for the decline in HIV prevalence in Uganda and developments in HIV prevention policy in the 1990s. While the reviewed literature has noted that the analysis of the Ugandan HIV surveillance data, supporting both formative explanations for the Ugandan HIV decline and HIV prevention policy development is contested, it has not generated detailed qualitative data from the HIV/AIDS experts who were directly involved with the creation of the original sources of evidence used to explain the Ugandan HIV decline, and to shape the direction of subsequent HIV prevention policy in the 1990s. To address this absence of empirical information, it is appropriate for this study to use SGS as a lens via which to examine the contested explanations for the decline in HIV prevalence in Uganda and the role of evidence in the development of global HIV prevention policy. Via this analysis it should be possible to complement the existing body of knowledge – including the research advanced by Parkhurst (2012) – to understand better the salience of individual agency and framing processes upon the use and interpretation of evidence in policymaking contexts at the national and global level. Having examined the role, and interpretation of, evidence in the formulation of HIV prevention policy in Uganda, it is now appropriate to explore additional factors that appear to influence the role of evidence in HIV prevention policy development from other LICs contexts.

## 2.6 The influence of political factors, policy entrepreneurship and policy networks on the role of evidence in HIV prevention policy pertaining to sub-Saharan Africa

To understand better the role of evidence in the development of HIV prevention policy, this section of the chapter critically examines key themes that emerged from the literature pertaining to sub-Saharan Africa. The reviewed literature indicates that three factors appear to influence the role of evidence in HIV prevention policy, namely: political factors, policy entrepreneurship and policy networks – each of which will now be

examined. Once analysed, the following sub-section will explore factors that influence the relationship between evidence and health policy pertaining to sub-Saharan Africa. This is important as it is claimed that the relationship between evidence and health policy, and factors that influence the dynamic itself, are poorly understood across sub-Saharan Africa and conceptual gaps in our understanding about the relationship remain (Woelk: 2009; Burris et al: 2011; Pang & Tharyan: 2009; Uneke et al: 2012; Ssengooba et al: 2011).

Buse et al (2006) note that political factors can influence the role of evidence in HIV prevention policy – and more broadly sexual and reproductive health policy – within LICs in sub-Saharan Africa. Indeed it is asserted that political factors can determine which reproductive and sexual health issues are included in national health policy agendas, which evidence is examined (or excluded), which policy alternatives are considered (and ultimately adopted), and the degree to which they are implemented (Buse et al: 2006: pp. 2101). Parkhurst (2012) echoes these notions arguing that HIV prevention policy development is an activity that cannot be pursued without making value judgements and is an inherently political process (Parkhurst: 2012: pp. 1). Acknowledging that there have always been political dimensions to HIV prevention policy development, it is reasoned that policy decisions relating to HIV often involve complex choices between competing and contested outcomes (Parkhurst: 2012: pp. 2). Thus, when reflecting upon the role of evidence in the development of HIV prevention policy, it is important to depart from simple conceptions of HIV prevention policy formulation and the idea that value-neutral assessments of evidence and ‘what works’, appraised solely in terms of HIV incidence reduction or proximal behaviour change, will determine policy outcomes in their own right (Parkhurst: 2012: pp. 2). Buse (2008) additionally contends that there is a common sense understanding that politics and, more broadly, distinct socio-political contexts are salient determinants of HIV policy and evidence utilisation. It is reasoned that those who seek to influence HIV prevention policy development must fully appreciate the political dimensions of HIV policy, asserting that failure to do so can frustrate efforts to promote and implement evidence-informed policy (Buse et al: 2008: pp. 572). Dickenson & Buse (2008)

also assert that as HIV has been a disease associated with sex and illegal drugs, HIV prevention policy formulation has been highly politicised from the outset of the HIV/AIDS epidemic (Dickenson & Buse: 2008: pp. 1). It is even claimed that in multiple contexts, politics, ignorance, and ideology have proven to be more influential on HIV policy development than evidence, epidemiological data, or technical best practice (Dickenson & Buse: 2008: pp. 1). It is reasoned by Dickenson & Buse (2008) that to conceptualise properly the role of evidence in the development of HIV prevention policy, one must stand back and first reflect upon the broader policymaking process.

Dickenson & Buse (2008) reason that the policymaking process should be understood in the context of ongoing interactions among institutions (the rules and structures which shape how decisions are made), ideas (discourses, arguments and evidence), and interests (the individuals and groups who stand to lose or gain from change (Dickenson & Buse: 2008: pp. 1). This conceptualisation of policymaking suggests that the role of evidence in the development of HIV prevention policy is inevitably complicated by conflicting values and competing interests, with evidence rarely speaking for itself in direct relation to HIV prevention. It is also asserted that the emergence of evidence and ideas, and how they are discussed and communicated amongst experts involved with HIV policy development, influences the content of HIV policies and how they are subsequently implemented in various policymaking contexts (Dickinson & Buse: 2008: pp. 4).

One study critically examines the influence of political factors upon the role of evidence in HIV prevention policy development within the context of Tanzania. Hunsmann (2012) notes that far from being strictly evidence-driven, HIV prevention policy within the country results from a politically negotiated aggregation of competing and frequently non-optimising rationalities amongst policymakers who possess different ideas about the prevention of HIV (Hunsmann: 2012: pp. 1477). It is reasoned that failure to consider the invariably political nature of HIV-related policymaking, particularly within LICs like Tanzania, impedes the creation of effective,

politically-informed strategies for positive change. Departing from the widely assumed notion of rational evidence utilisation within policymaking, it is reasoned that it is important to develop policy practitioners' understanding of how to engage in evidence-informed political struggles over priorities, and to appreciate that technical approaches to HIV prevention will be influenced by political controversies that occur amongst policymakers (Hunsmann: 2012: pp. 1477). Via the critical analysis of allocative decisions regarding HIV prevention within Tanzania, it is asserted that political constituencies, the vertical nature of the Tanzanian HIV response, the expected timeline of interventions' political returns, and economic cost all downgrade the influence of evidence within the policymaking process. It is significant to note that these factors conspire to influence the creation of Tanzanian HIV prevention policies in ways that are drastically at odds with rationalist decision-making models (Hunsmann: 2012: pp. 1482). It is claimed that Tanzanian HIV prevention policies are not wholly evidence-driven, arguing against apolitical conceptions of health policy formation within this particular sub-Saharan African country.

It is also maintained that rationalist conceptualisations of policymaking in direct relation to HIV prevention policy are essentially a fallacy or idealised form of policymaking that fail to demonstrate real-world understandings of decision-making processes, especially within LICs like Tanzania (Hunsmann: 2012: pp. 1483). Indeed, it is asserted that HIV prevention policies, at least within the context of Tanzania, are primarily based on politics and that ignoring the political nature of HIV prevention policy exposes actors involved with HIV / AIDS policy to repeated frustrations, which impedes the formulation of politically informed strategies for positive change (Hunsmann: 2012: pp. 1484). Hunsmann's (2012) study is useful to consider as it provides a realistic appraisal of policymaking processes and the complex role of evidence in HIV prevention policy development within sub-Saharan Africa. It possesses an additional analytical strength as it argues for in-depth understandings of policymaking processes within sub-Saharan Africa, and the importance of examining the complexity surrounding the heterogeneous influence of politics upon evidence and subsequent policy

formation within the region. It is reasoned that future research that seeks to examine evidence utilisation within sub-Saharan Africa should go beyond solely examining the underlying bio-epidemiological rationalities of HIV policy, to examine competing dialectics at play in the formulation of HIV policy and their selective, politically mediated, implementation (Hunsmann: 2012: pp. 1483).

Analysis of literature pertaining to sub-Saharan Africa suggests that policy entrepreneurship can also influence the role of evidence in HIV prevention policy development. Prior to advancing, it is required to define policy entrepreneurs and the idea of policy entrepreneurship. Policy entrepreneurs can be defined as individuals who possess a specific claim to hearing within distinct policymaking networks or broader policymaking domains. This claim to hearing is underpinned by up to three sources: their individual expertise, their ability to speak for others, and/or their authoritative decision-making position (Kingdon: 1995: pp. 180). According to Kingdon (1995), there maybe an array of individuals who float within the policymaking process, however policy entrepreneurs are the central actors who can capture the attention of others in order to promote their personal interests and their intended policy objectives (Kingdon: 1995: pp. 123). Policy entrepreneurs possess four central qualities which can facilitate their ability to develop their intended policy goals, namely: their negotiating skills, their political connections, their tenacious nature which permits them to push their ideas about policy problems (and how to address them in multiple fora) and the possession of a known level of expertise, which again gives them a legitimate claim to hearing within distinct policy networks (Kingdon: 1995: pp. 180 – 181). The primary motivation for policy entrepreneurs to function within the broader policymaking process is driven by the promotion of personal self-interest, which can include the imperative to protect one's own bureaucratic turf, to maintain one's employment, to expand one's individual agency, and/or to advance personal career promotion (Kingdon: 1995: pp. 123). One study has highlighted the influence of policy entrepreneurship upon the role of evidence in HIV prevention policy formation within the context of Ghana.

Burris et al (2011) examined the influence of policy entrepreneurship upon the role of evidence, and more broadly the relationship between evidence and HIV health policy, in Ghana. They specifically explored how evidence which related to HIV/HSV-2 interactions shaped policy development at the international level, and the mechanisms of international to national policy transfer, using aspects of HIV policy in Ghana as a case study. Significantly, they noted the function of policy entrepreneurs as playing recurrently important roles in driving policy change, and how evidence alone was insufficient to influence policy without the engagement and alignment of multiple factors (Burris et al: 2011: pp. 8). Indeed, they discovered that a well-placed policy entrepreneur within the Ghanaian Ministry of Health or the National HIV control Program was a particularly effective agent for using operational research findings to change policy (Burris et al: 2011: pp. 7). However, for a policy entrepreneur to bring about policy change on the grounds of operational research evidence, the intended policy change needed to: (a) save money in the long run, (b) be highly visible and good for public relations, (c) be beneficial to the population at no extra cost, or (d) have any extra costs covered by donor agencies, and/or (e) have the potential to attract donor funding (Burris et al: 2011: pp. 7).

The authors reasoned that these conditions were essential prerequisites for generating the political will needed to bring about policy change within Ghana in relation to HIV. Based upon their qualitative interview data, Burris et al (2011) found that policy entrepreneurs could carry issues and operational research into broader policy networks, where personal ties with either colleagues or old friends acted as the main route to the latest research findings which, in turn, could generate internal pressure for policy to change (Burris et al: 2011: pp. 7). Usefully, this study displayed the key function of policy entrepreneurs in influencing the role and utilisation of research evidence and subsequent Ghanaian HIV/HSV-2 policy reform, specifically noting their critical function in bridging the gap between research evidence and policy itself (Burris et al: 2011: pp. 7). Having examined the impact of policy entrepreneurship upon the role of evidence in the development of HIV prevention policy, it is now appropriate to explore the influence of

policy networks and their impact upon the role of evidence in HIV prevention policy development.

In addition to noting policy entrepreneurs' influence upon the role of evidence in relation to HIV policy in Ghana, Burris et al (2011) acknowledged the pivotal influence of policy networks in functioning as the primary conduit of information exchange between researchers and policymakers at both international and domestic levels (Burris et al: 2011: pp. 1). Their study maintained that communication between research and policymaking networks was critical for the uptake of evidence and how evidence was utilised by experts in relation to HIV/HSV-2 policy development. They claimed that once evidence of a synergy between HIV/HSV-2 had accumulated through observational data and meta-analyses a policy network of program managers, policymakers, and researchers took it upon themselves to drive the policy agenda (Burris et al: 2011: pp. 5). Their study identified that interactions between researchers and policymakers involved with HIV/HSV-2 policy change at the Ghanaian and international levels (including expert decision-makers from the WHO) were characterised by a club-like camaraderie, and links between key networks of actors were essential in shaping the function of evidence within the broader policymaking process in both contexts.

It was understood that these interactions played an important role in the influence of evidence on HIV policy, through the formation of policy networks at global (WHO) and national (Ghanaian) levels. The authors note that policy networks, and policy entrepreneurs operating within the networks themselves, provided the primary impetus for policy change in relation to HIV policy, suggesting that evidence alone was insufficient to shape policy development (Burris et al: 2011: pp. 8). It was also ascertained that researchers involved with HIV relied upon their friends, who held key policymaking positions, to be instrumental in the researchers' attempt to develop policy which, it is argued, constituted a policy network—one that linked researchers with well-placed policymakers who were then able to influence subsequent policy development (Burris et al: 2011: pp. 7).



Significantly, this study maintained that communication amongst policymakers and researchers was of critical importance in facilitating the uptake of evidence, with policy networks themselves functioning as the key force to catalyse policy change in relation to HIV policy in the international (WHO) and national (Ghanaian) contexts (Burris et al: 2011: pp. 1).

#### *2.6.1 Factors influencing the relationship between evidence and health policy pertaining to sub-Saharan Africa*

Having examined the influence of political factors, policy entrepreneurship, and policy networks on the role of evidence in HIV prevention policy development, it is now required to examine their influence upon the broader relationship between evidence and health policy pertaining to other sub-Saharan African contexts. This exploration is needed as HIV policy falls under the broader rubric of health policy, thus an analysis of the relationship between evidence and health policy in other sub-Saharan African contexts can increase conceptual understandings of the role of evidence in policy development within this under-researched geographical area. In line with the literature examined above, three factors appear to influence the role of evidence in health policy pertaining to sub-Saharan Africa, namely: political factors, policy entrepreneurship, and policy networks – each of which will now be examined.

Within the setting of Nigeria, in a study aiming to promote evidence-informed health policymaking within the country, it was noted by Uneke et al (2010), that a number of political barriers influenced the translation of research into policy and practice via evidence use. Specifically: an absence of relevant research data, interdisciplinary conflicts (meaning a lack of interdisciplinary team work between researchers and policymakers), and a lack of knowledge on the part of policymakers to appreciate the relevance of evidence-based research (Uneke et al: 2010: pp. 3).

Additional barriers that influenced the use of evidence within health policy development in Nigeria included communication gaps and poor networking between policymakers and researchers, and capacity constraints at individual and organisational levels. Uneke et al (2012) claim that one of the central political issues which complicates the process of evidence/policy translation within Nigeria stems from ‘huge gaps’ between researchers and policymakers. They contend that one of the central challenges to the successful implementation of EBPM within Nigeria, stems from incompatibilities existing between researchers and policymakers. It is asserted that researchers operating within LICs, like Nigeria, lack knowledge of the policymaking process and they often produce research evidence that is irrelevant to the policymaking process itself (Uneke et al: 2012: pp. 2). It is reasoned by Uneke et al (2012) that the promotion of EBPM within LICs in sub-Saharan Africa cannot be achieved without ‘bridging the gap’ between researchers and policymakers (Uneke et al: 2012: pp. 14). While Uneke et al (2010; 2012) identify some relevant political barriers that can impede the utilisation of evidence and subsequent policy development, their studies are influenced by underlying rationalist and normative assumptions about the function of evidence within policymaking in the context of sub-Saharan Africa. Indeed, their 2012 study was implemented with a normative desire to promote EBPM within the context of Nigeria—as outlined within the introduction of their investigation:

This study was designed to promote evidence-informed policymaking and improve the capacity of policymakers and other stakeholders to acquire, assess, adapt and apply research evidence effectively. This study was also designed to facilitate linkage and exchange among the major players in Nigerian health policymaking arenas (policymakers, researchers and other stakeholders) and to bridge the huge gap existing between policymakers and researchers (Uneke et al: 2012: pp. 3)

The study therefore assumes that EBPM can be realised within LICs, like Nigeria, by building links and enhancing partnerships between researchers and policymakers. The ideas advanced by Uneke et al (2012) resonate with notions relating to the use, and non-use, of evidence by policymakers and

researchers involved within the process of decision-making, as advanced by Caplan in the late-1970s. Caplan (1979) sought to explain the use, or non-use, of evidence by actors involved within the process of decision-making. It was reasoned that researchers and policymakers operated in two communities and reasons contributing to the non-use of research evidence stemmed from cultural gaps between the two groups. Caplan reasoned that social scientists were directly concerned with esoteric issues and pure science, while policymakers were more action-oriented, being more practical and concerned with more obvious and immediate issues (Caplan: 1979: pp. 459). Although one can argue that researchers and policymakers operate in different fora, the two communities model can be criticised, as it is based on a simple dichotomous relationship between the use versus non-use of research evidence within the broader policymaking process (Neilson: 2001: pp. 3). The two communities notion, which Uneke et al (2012) appears to endorse, is potentially problematic as policymaking processes and divisions of labour between researchers and policymakers are more amorphous than this model suggests, since researchers are often simultaneously operating as policymakers, especially within LICs in sub-Saharan Africa. While this study accounts for some political barriers that influence the movement of evidence within the policymaking process (interdisciplinary conflicts, a lack of knowledge by policymakers to appreciate the relevance of evidence-based research, and an absence of relevant research data at the country-level), it possesses strong normative commitments to the notion and practice of EBPM within the context of Nigeria. This should be viewed with caution, as it has been established that the relationships between evidence and health policy within other sub-Saharan African countries are both complex and inherently political.

Within the context of Uganda, Orem et al (2014) attempted to examine the role that evidence played in relation to malaria treatment policy change. Their study noted that evidence was utilised to adapt malaria treatment policy within the country, however the consistency between evidence and policy decisions varied along the policy development cycle (Orem et al: 2014: pp. 1). Their study acknowledged that changes in malaria treatment policy

within Uganda were reported to be very technical, with the role of evidence seen as being very important (Orem et al: 2014: pp. 1). The sources of evidence that were apparently considered were categorised into nine areas including: local and international evidence on drug efficacy, guidance from the WHO, cries from the community<sup>1</sup>, evidence on cost, implementation feasibility, local and international experiences, observational evidence, routine monitoring data, and evidence on behavioural change (Orem et al: 2014: pp. 6). While different kinds of evidence were seen as informing policy change in relation to malaria treatment policy, certain political factors were noted as inhibiting the uptake of evidence within the country. In particular: resistance from implementers, including health workers involved with domestic malaria treatment policy change, and the Ugandan health systems' capacity to implement the new policy and its financial sustainability (Orem et al: 2014: pp. 12 – 13). In relation to individual level factors (resistance from health workers), it was discovered that certain individuals involved with malaria treatment were not willing to adjust established behaviours in relation to the treatment of malaria itself, which highlights the role of individual agency in the non-use of evidence within the context of Uganda (Orem et al: 2014: pp. 12). More broadly, issues with the Ugandan health system, and a perceived lack of sustainability regarding the new malaria treatment policy, were seen as additional barriers to the uptake of evidence. Specifically, concerns existed in relation to the supply chain system that would ensure the availability of artemisinin combination therapy within the country and there was doubt as to whether the policy could be sustained on the basis of Ugandan financial resources (Orem et al: 2014: pp. 12). Usefully, this study explored how political factors influenced the uptake of evidence in relation to malaria policy development. Via a qualitative case study methodology (involving interviews with key informants) and document review, this study demonstrated that a diverse range of stakeholders played various roles and gained different levels of influence upon the uptake of evidence in relation to malaria treatment policy change. Having examined the influence of political factors upon the relationship between evidence and

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<sup>1</sup> Cries from the community referred to requests from the Ugandan public to take action in relation to malaria (Orem: 2014: pp. 6)

health policy within the contexts of Nigeria and Uganda, the chapter now turns to the concept of policy entrepreneurship and its influence on the evidence/health policy dynamic within the region of sub-Saharan Africa.

One study has highlighted the influence of policy entrepreneurship upon the relationship between evidence and health policy within sub-Saharan African policymaking contexts. Noting that few empirical studies of research utilisation have been implemented within LMICs, Daniels & Lewin (2008) explored how research evidence influenced policy decisions around the use of magnesium sulphate in the treatment of eclampsia and pre-eclampsia in South Africa (Daniels & Lewin: 2008: pp. 1). Adopting a qualitative case-study approach, they noted the importance of policy entrepreneurship in using research evidence in shaping maternal health care policy development and in placing issues on the policy agenda. They discovered that local researchers from South Africa functioned as policy entrepreneurs, bringing attention to priority health issues and influencing the use of evidence to bring about policy change in relation to maternal healthcare policy (Daniels & Lewin: 2008: pp. 1). Usefully, this study reflected upon the national political environment within South Africa and how the political climate during apartheid prevented policy entrepreneurs from gaining attention in ways that would achieve meaningful policy change in relation to maternal healthcare policy (Daniels & Lewin: 2008: pp. 10). When the political climate changed with the demise of the apartheid regime in 1994 however, individuals with strong links and the relevant expertise were appointed to key positions in maternal healthcare and were thus able to function as policy entrepreneurs to bring about policy change via the strategic use of evidence (Daniels & Lewin: 2008: pp. 10). This study makes a valuable contribution to the limited literature on factors influencing the uptake of evidence into policymaking within South Africa, highlighting the importance of a conducive domestic political environment upon the policy entrepreneurs involved with the utilisation of evidence and subsequent policy development. This study helpfully contextualised the activities of policy entrepreneurs against a broader political climate of receptivity, and the salience of external political change upon the ability of individuals involved

within maternal healthcare policy development, to use evidence to drive meaningful policy change. It therefore demonstrates the importance of considering macro-level political factors in exploring the role of policy entrepreneurs, making clear that the use of evidence within distinct policy networks can be influenced by broad adaptations in domestic political systems.

The third key factor that can influence the relationship between evidence and health policy within sub-Saharan Africa are policy networks. This section examines one article that highlights policy networks' role in the way evidence helps shape health policy development within sub-Saharan Africa, and their function in facilitating policy change by placing key issues on the policy agenda in various countries within the region. Examining two policy case-studies focused on the use of magnesium sulphate in the treatment of eclampsia in pregnancy (a clinical case) and the use of insecticide treated bed nets and indoor household residual spraying for malaria control (a public health case), Woelk et al (2009) attempted to examine factors influencing the use of evidence in national policy development in three sub-Saharan African countries. Using Mozambique, South Africa, and Zimbabwe as country case studies, they discovered that policy networks were important in the utilisation of evidence in both the clinical and public health case studies (Woelk: 2009: pp. 1). In relation to the eclampsia case study, it was discovered that academic obstetricians, who were important to local policy development, were involved in national, regional, and international research networks (Woelk: 2009: pp. 7). Importantly, these networks were seen as key to creating a culture of research and evidence-based medicine by exposing local level clinicians to new ideas as they developed internationally. It is reasoned both directly and indirectly that these networks shaped the translation of evidence into policies, whilst building links to leading research taking place at the international level (Woelk: 2009: pp. 7).

Regarding the use of insecticide treated bed nets compared with indoor household spraying for malaria vector control, they found that policymakers and researchers were organised into strong regional networks that were important in sharing approaches and ideas for malaria control (Woelk: 2009:

pp. 9). It was also found that while policymakers involved with malaria control became aware of evidence through their own reading, a range of additional interfaces were also significant in terms of how evidence informed the policymaking process. In all three countries, researchers were co-opted into formal government advisory committees which consequently led to the creation of close relationships between health officials and researchers for implementing malaria treatment control (Woelk: 2009: pp. 9). It is argued that the influence of national, regional, and international research and policy networks, in relation to the routes through which research evidence entered the policymaking process, were important in both the eclampsia and malaria case studies (Woelk: 2009: pp. 11). However, the nature and the size of the policy networks involved with the two case studies varied dramatically. Indeed, in the eclampsia case study the authors noted that researchers and obstetricians in all three countries often belonged to the same national clinical and research networks, attending the same conferences and meetings (Woelk: 2009: pp. 11). They contend, in relation to the eclampsia case study, that a tightly knit group, which they defined as a policy community, was key in ensuring a homogenous conceptualisation of evidence, for providing resources, and for lobbying and facilitating knowledge exchange (Woelk: 2009: pp. 11). The existence of these tightly knit national policy communities (made up of a small number of clinicians with similar disciplinary backgrounds and training) was seen as important in facilitating consensus around research evidence in relation to the eclampsia case study (Woelk: 2009: pp. 11).

Distinct from the eclampsia case study, however, Woelk et al (2009) identified a wider array of stakeholders within the malaria control domain, with groups from divergent backgrounds possessing different interests and opinions. Members of these policy networks were described by Woelk et al (2009) as an unruly *mélange* of political actors and interest groups, who frequently contested existing and novel interventions whilst championing different causes based upon ideological and political interests (Woelk: 2009: pp. 11). In debates over malaria control, including which specific insecticide to use and whether or not to use bed nets or spraying, various groups

aligned to different positions, with pro- and anti-spraying groups being present in all three countries (Woelk: 2009: pp. 11).

The authors maintain that the differences found between the eclampsia and malaria policy networks relates to the distinct nature of the two issues. Indeed, it is argued that eclampsia is a focused clinical condition which therefore has a narrow footprint, in the sense that the number of actors involved was fairly compact. Common understandings of the research evidence were therefore easily achieved, based on close working relationships (Woelk: 2009: pp. 11). In contrast, the malaria control case study had a broad footprint with a very wide range of actors with diverse agendas, in both the research and policy areas, making the development of a common understanding of evidence more difficult (Woelk: 2009: pp. 11). Helpfully, this study acknowledged that the movement of evidence and its influence on policy is a complex and context sensitive process, arguing that researchers seeking to examine evidence and the process of knowledge translation itself within sub-Saharan Africa need to be aware of policy networks' influence upon the evidence/policy dynamic (Woelk: 2009: pp. 2). It also demonstrated that larger policy networks made up of experts from divergent backgrounds possessed competing interests, which made the process of gaining consensus over evidence more difficult in direct relation to malaria treatment policy change. It therefore demonstrated how heterogeneous policy networks, as opposed to more homogenous policy networks, complicated the movement of evidence within the broader policymaking process.

## 2.7 Discussion of key findings and chapter summary

The literature reviewed within this chapter demonstrated that the role of evidence in the formulation of HIV prevention policy can be influenced by an array of complex factors. The salience of political factors, policy entrepreneurship, and policy networks were noted as key in shaping the role of evidence in HIV policy development and more broadly the relationship



between evidence and health policy, pertaining to various countries in sub-Saharan Africa. In combination, these factors serve as a reminder that rationalist or linear understandings of the evidence/policy connection should be viewed with caution, as they are likely to complicate how evidence is used within the broader policymaking process itself.

Relating to the interpretation and use of Ugandan data in the formulation of HIV prevention policy in the 1990s, it was demonstrated that HIV surveillance data were utilised in both a heterogeneous and at times highly partisan manner, by HIV/AIDS experts involved with HIV policy development in this specific period of time. It was also discovered, via an analysis of Parkhurst (2012), that the role of evidence in HIV prevention policy development can be influenced by complex cognitive framing processes and by an individual's ideas and beliefs about sexual behaviour. It is clear on the basis of literature from Uganda that HIV surveillance evidence was used to support particular approaches to subsequent HIV prevention policy development, with debates taking place in relation to the broader ABC prevention policy approach to HIV that emerged in the mid 1990s.

While the studies examined above provided an account of the complexity surrounding the interpretation of Ugandan HIV surveillance data and the subsequent direction of HIV prevention policy, they have not generated qualitative data from the cohort of Ugandan and global level HIV/AIDS experts who were involved with the generation, analysis, and utilisation of the original sources of evidence used to explain Uganda's HIV decline, and subsequently to shape the direction of HIV prevention policy in the 1990s. To address this absence of empirical information, it is appropriate for this study to use SGS as a lens via which to examine the contested explanations for the decline in HIV prevalence in Uganda, and the role of evidence in the development of global HIV prevention policy. Via this analysis it should be possible to complement the existing body of knowledge, including the research advanced by Parkhurst (2012), to understand better the salience of individual agency and framing processes upon the use and interpretation of evidence in policymaking contexts at the national and global level. As noted

above, Hunsmann (2012) demonstrated that the relationship between evidence and policy in direct relation to HIV prevention policy, was influenced by competing rationalities among HIV/AIDS prevention experts and the broader influence of politics upon evidence and subsequent policy development. It is reasoned by Hunsmann (2012) that future research seeking to examine the role of evidence in policy development needs to go beyond the sole *content* of HIV policies and their underlying bio-epidemiological rationalities to examine competing dialectics at play in the *formulation* of HIV policies and their selective, politically mediated implementation (Hunsmann: 2012: pp. 1483). The current study thus aims to address Hunsmann's call by further exploring the political determinants of HIV/AIDS policy by attempting to open the conceptual black box of 'political factors', to provide a more nuanced account of the contestation surrounding explanations for the decline in HIV prevalence in Uganda, and the role of evidence in the development of global HIV prevention policy in the 1990s.

## **CHAPTER THREE: Methodology**

### **3.1 Introduction to chapter**

This chapter explains the methodological approaches selected to examine contested explanations for the decline in HIV prevalence in Uganda and the role of evidence in the development of global HIV prevention policy in the 1990s. It commences with an examination of the role of qualitative methodological approaches within the field of public health, elucidating their utility in relation to the critical analysis of the contested Ugandan HIV prevalence decline and the use of SGS as a case study—discussing the strengths of the case study method for addressing the central thesis aim. The process of identifying documents for review, and the purpose of documentary analysis is then presented. The function of semi-structured interviews with elites, the tools used for data collection and the approach adopted for data analysis are outlined. The process of securing Uganda National Council of Science and Technology (UNCST) research clearance is clarified. A concise discussion of University of Edinburgh School of Social and Political Science (SSPS) ethical protocols that were addressed prior to the data collection phase of this study, will also be given. Epistemological and ontological reflections are discussed, and issues pertaining to researcher reflexivity are posited.

### **3.2 Function of qualitative methodological approaches within the field of public health**

Qualitative methodological approaches have been used in this study reflecting the inherent complexity of the public health field which is full of puzzling questions, slowly evolving events, and complicated relationships – phenomena leaving gaps in understanding that invite qualitative methods to fill (Rubin & Rubin: 1995: pp. 51). In addition to addressing puzzling questions, qualitative methodological approaches, and qualitative

researchers alike, seek to confront complex problems in the real world by gathering what they hear, observe and read from places and people with the aim of learning about specific facets of the social world itself (Rossman & Rallis: 1998: pp. 5). Via the use of qualitative methodological approaches, it is also possible to examine key components of the social world which, in turn, can facilitate novel understandings that can be used by the social world itself (Rossman & Rallis: 1998: pp. 5). These notions indicate that qualitative methodological approaches can be used to explore puzzling questions of interest in order to create new ideas about the social world itself – particularly within the field of public health.

As this project seeks to examine a complex research aim, namely to examine contested explanations for the decline in HIV prevalence in Uganda, and the role of evidence in the development of global HIV prevention policy in the 1990s via the analysis of SGS, qualitative approaches have been selected to facilitate an exploration of this multifaceted subject matter. As demonstrated within the preceding chapters, the role of evidence in the development of HIV prevention policy, and the contestation surrounding the Ugandan HIV prevalence decline of the 1990s, is inherently complex. Given the complexity of the subject matter under analysis, it is appropriate to use qualitative methodological approaches within this project as they can enable the researcher to examine the contested Ugandan HIV decline and the subsequent development of HIV prevention policy in the 1990s in an analytically rigorous manner.

An additional reason supporting the use of a qualitative approach in this project, pertains to methodological choice. In relation to particular methods that can be implemented when using a qualitative research design, public health researchers are faced with a plethora of approaches from which they can pick those methods most likely to generate the most valid and comprehensive answers (Baum: 1995: pp. 465). While noting that a range of qualitative methods are available to help examine puzzling questions of interest within public health research, it is necessary to outline the key

qualitative method that underpins the research project in its totality—namely the case study approach.

### 3.3 Adoption of a case-study approach

To examine how explanations advanced for the decline in Ugandan HIV prevalence were contested and how this contestation affected broader HIV prevention policy development in the 1990s, a case study – namely SGS – was selected. Due to the centrality of the case-study approach within the project, it is required to justify why this specific method was used to facilitate an exploration of its analytical subject matter under investigation. A case study approach is useful when asking how or why questions, when one has little control over events and when the focus of research is on a contemporary phenomenon within a real-life context (Yin: 2009: pp. 2). The central area of analytical investigation within this project is the critical examination of the contested Ugandan HIV prevalence decline and the development of HIV prevention policy in the 1990s. Thus, a clearly identifiable policy case study was needed to allow the researcher to explore this complex subject matter in analytical detail. The emergence of SGS was selected as a lens via which to examine the contested Ugandan HIV decline, and the development of HIV prevention policy in the 1990s, as it is a clearly identifiable policy initiative supported by behavioural evidence from Uganda itself – behavioural evidence that was used to shape formative accounts for the contested Ugandan HIV prevalence decline in the 1990s. Therefore, this policy case was a suitable vehicle to permit the researcher to analyse how broader explanations advanced for the decline in Ugandan HIV prevalence were contested, and why particular explanations informed the development of global HIV prevention policy in the 1990s.

As a research method, the case study approach can be used in multiple contexts in order to contribute to knowledge about individual, group, organisational, political and social related phenomena (Yin: 2009: pp. 4). The case study method also permits researchers to examine the meaningful

characteristics of real life events including individual life cycles, small group behaviour and organisational processes (Yin: 2009: pp. 4). It also permits researchers to undertake in-depth and multifaceted explorations of complicated problems in their real-life settings, which is especially useful when one needs to obtain detailed appreciations of an issue, event or phenomenon of interest in its natural context (Crowe et al: 2011: pp. 1). Importantly, the case study approach also allows events, interventions and policy developments to be studied in critical detail (Crowe et al: 2011: pp. 8). As the case study approach can facilitate the detailed study of complex problems – including policy developments – it was justifiable to select this particular methodological approach as the subject matter under examination within this project – namely contested explanations for the Ugandan HIV prevalence decline – is acknowledged as being a complex area of research to analyse. Prior to advancing, it is necessary to describe how SGS was located for analysis (this involves a concise description relating to the evolution of this research project itself). Once outlined, the function of documentary data analysis, and its role in helping to examine the evidence used to support the development of SGS will be advanced.

The specific case-study on which this research is based developed over a two-year period, partly in response to emerging issues with evidence and claims about evidence in relation to the development of SGS. Based within the Centre for International Public Health Policy, my original research project aimed to assess critically the evidence-base used to generate the global burden of disease (GBD) estimates for HIV/AIDS in Uganda<sup>2</sup>. It was a specific objective of my original research project to locate and analyse the evidence-base that had supported the GBD estimates for HIV/AIDS—critically assessing their empirical validity from an epidemiological and quantitative analytical perspective. However, in the early stages of my research, difficulties arose in locating the Ugandan epidemiological data sources that were used to generate the GBD figures for HIV/AIDS within the

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<sup>2</sup> Uganda was used as a case study country as my former supervisor was researching and working with colleagues from Uganda as part of the Accessing Medicines in Africa and South Asia (AMASA) project.

country. In reaction to my inability to locate the Ugandan HIV/AIDS epidemiological data sources for critical appraisal, a modification in my research direction was required. Importantly, however, in the process of reviewing HIV/AIDS surveillance reports produced by the Ugandan Ministry of Health, as part of my original GBD research project, the term ‘Second Generation Surveillance’ kept appearing. For example, within a Ugandan Ministry of Health HIV/AIDS surveillance report published in 2001 it was stated that:

We are routinely collecting data on HIV/AIDS surveillance as part of Second Generation Surveillance to get a better understanding of the behavioural context in which the epidemic is progressing (Ugandan Ministry of Health: 2001: pp. 1).

The commitment to SGS was reaffirmed in another HIV/AIDS surveillance report that was published by the Ugandan Ministry of Health in 2009:

HIV surveillance in Uganda is conducted in the context of second generation surveillance whereby the HIV biological surveillance data are complemented by data from behavioural surveillance, STI, and AIDS case surveillance as well as programmatic monitoring, evaluation and operational research (Ugandan Ministry of Health: 2009: pp. 1).

Significantly, the term ‘Second Generation Surveillance’ immediately attracted my interest and it raised some profound questions. If there is a ‘second generation’ of HIV surveillance what was the first generation? What is SGS and how was evidence supporting its introduction mediated by experts involved with its formal development? Which institutions developed SGS and why was it being used in Uganda? In reaction to these questions, time was taken to research SGS and the evidence supporting its formal introduction. After rudimentary online literature searches and formative document review, it became clear that SGS was introduced by UNAIDS/WHO in 2000—supported mainly by evidence from Uganda. Reflecting upon SGS further, I realised that it could be used as a policy case study to understand the acknowledged contestation that surrounds the Ugandan HIV/AIDS decline and the subsequent development of HIV

prevention policy in the 1990s. Thus, more time was taken to locate relevant policy documentation pertaining to the development of SGS—the process of which will now be described in detail.

### 3.4 Selection and analysis of documentary data

To facilitate an examination of contested explanations for the decline in HIV prevalence in Uganda and the role of evidence in the development of global HIV prevention policy, it was important to locate, and analyse, relevant SGS policy documentation. To locate policy documentation, directly pertaining to SGS, the search engine Google was used to identify germane sources of policy material. Searches on Google including: “Second Generation HIV Surveillance” and “Second Generation Surveillance” were inputted—using quotation marks (to search for these exact phrases and to reduce the potential number of hits). These simple searches, as expected, yielded a vast amount of hits (6,540 for “Second Generation HIV Surveillance” and 14,300 for “Second Generation Surveillance”). Naturally, it was not possible to review all of the information from the search terms inputted on Google. Thus, the researcher only focused on hits that made direct reference to SGS on the first page of retrieved results—sources were also excluded for analysis if they took the form of editorials and commentaries. The top hit for both of the search terms above was an official WHO webpage<sup>3</sup> which provided a concise description of SGS, a list of key reference material and a link to another webpage where additional sources of information about SGS were provided<sup>4</sup>. Via the use of Google, and simple key word searches, relevant policy documentation which directly pertained to the development of SGS were located. Key sources of documentation located via the WHO website are as follows:

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<sup>3</sup> <http://www.who.int/hiv/topics/surveillance/2ndgen/en/>

<sup>4</sup> <http://www.who.int/hiv/strategic/surveillance/en/>



Table 4: SGS related documentation

1. World Health Organization and UNAIDS. Second generation surveillance for HIV: compilation of basic materials. CD-ROM. Geneva, World Health Organization (WHO/HIV/2002.07). 2002
2. World Health Organization and UNAIDS. Initiating Second Generation HIV Surveillance Systems: Practical Guidelines. Geneva, World Health Organization (WHO/HIV/2002.17). 2002
3. World Health Organization and UNAIDS. Guidelines for Second Generation HIV Surveillance for HIV: The Next Decade. Geneva, World Health Organization (WHO/CDS/EDC/2000.05). 2000
4. World Health Organization and UNAIDS. AIDS Epidemic Update: December 2002. Geneva, World Health Organization (ISBN 9291732532). December 2002.
5. World Health Organization and UNAIDS. Report on the Global HIV/AIDS Epidemic 2002. Geneva, World Health Organization (ISBN 9219731854). July 2002.
6. UNAIDS Best Practice Collection. Trends in HIV Incidence and Prevalence: Natural Course of the Epidemic or Results of Behavioural Change? Geneva, UNAIDS (UNAIDS 99.12e). June 1999.
7. UNAIDS Best Practice Collection. Connecting Lower HIV Infection Rates with Changes in Sexual Behaviour in Thailand: Data Collection and Comparison. Geneva, UNAIDS (UNAIDS 98.15). June 1998.
8. UNAIDS Best Practice Collection. A Measure of Success in Uganda: the Value of Monitoring both HIV Prevalence and Sexual Behaviour. Geneva, UNAIDS (UNAIDS 98.8). May 1998.

As a social research method, document analysis is recognised as a useful tool for gaining nuanced understandings of complex issues whilst helping researchers to study specific research phenomena, events, organisations and policy programmes in detail (Bowen: 2009: pp. 29). The analysis of documents also permits researchers to discover meaning, to develop understanding, and to discover critical insights into specific research problems (Bowen: 2009: pp. 29). Thus, it was appropriate to locate, and examine, key sources of documentation to help address the core research aim of the project, namely the wish to explore the contestation surrounding the decline in Ugandan HIV prevalence – via the analysis of SGS – and the role of evidence in the development of global HIV prevention policy. Documents were analysed within this project for two core reasons. First, to gain formative understandings of SGS, its evidence-base and the actors – both individual and institutional – involved with its policy genesis. Second, to locate the names of HIV/AIDS experts who were cited as being involved with the development of SGS and its underlying evidence-base.

Document analysis was therefore important in helping to gain formative understandings of SGS's development, background to the Ugandan HIV prevalence decline, and to commence the process of identifying possible participants for interview. The approach taken to documentary analysis was informed by a thematic analysis approach. This particular form of analysis can facilitate pattern recognition, with emerging themes becoming the categories for analysis (Fereday & Muir-Cochrane: 2006: pp. 4). The process of thematic analysis requires a judicious, focused reading and review of the documentary data on multiple occasions (Bowen: 2009: pp. 32). While thematic analysis often involves coding and category construction, the purpose of the thematic analysis of SGS documentation was conducted to capture key overarching themes, recurring concepts, chronological information and to identify those key actors involved with the development of SGS itself. The analysis of documentation, in the early stages of the research project, was thus key in providing detailed understandings of SGS, and it enabled the researcher to commence the process of targeting participants for interview.

### *3.4.1 Process of identifying participants for interview*

UNAIDS/WHO documentation pertaining to SGS were reviewed to locate electronic contact information. Email addresses, that were located via document analysis, were used to send messages to both UNAIDS and the WHO (including: [hiv-aids@who.int](mailto:hiv-aids@who.int), [unaids@unaids.org](mailto:unaids@unaids.org), [publications@who.int](mailto:publications@who.int), [info@who.int](mailto:info@who.int) and named HIV/AIDS experts published in the documentary material—usually found within the acknowledgments section). The emails sent to the addresses above initially made requests to locate additional sources of evidence which supported the development of SGS, and to gain a copy of the CD-ROM described in the list above (as it provided a compilation of basic materials that related to SGS). In the process of this email exchange the researcher secured access to two gatekeepers (one from UNAIDS and one from the WHO). These gatekeepers were emailed project information and were notified of my intent to conduct semi-structured interviews with HIV/AIDS experts directly involved with the development of SGS and the analysis of behavioural data used to create explanations for the Ugandan HIV decline of the 1990s. Usefully, one of the gatekeepers was directly involved with SGS and acted on my behalf to contact other HIV/AIDS experts within UNAIDS/WHO. In a short space of time, one of the gatekeepers had contacted other HIV/AIDS experts involved with SGS (and forwarded on my project information electronically which explained my wish to examine SGS, the Ugandan HIV decline, and the role of evidence in supporting its formal development).

Thus, gatekeepers were used to help the researcher secure access to HIV/AIDS experts who had been directly involved with the development of SGS, and more broadly the analysis of the Uganda HIV prevalence decline, within UNAIDS/WHO in the 1990s. On the basis of suggestions advanced by one of the gatekeepers, a meeting was arranged at the headquarters of UNAIDS to liaise in person and to allow the researcher to hand out project information sheets and consent forms to HIV/AIDS surveillance experts in the headquarters of UNAIDS and the WHO. Once in Geneva, the researcher worked with the gatekeeper to implement a snowball sampling technique.

Snowballing is noted as being an effective technique for locating participants by asking others to identify individuals, or groups, with special understandings of specific phenomena (Ulin et al: 2005: pp. 58). It must be noted that the researcher was able to interact in a productive manner with the gatekeeper from UNAIDS, this subsequently enabled the researcher to meet other HIV/AIDS surveillance experts, to discuss my research project and to target potential participants for interview via snowballing. Discussions with the gatekeepers – and other HIV/AIDS experts within UNAIDS/WHO – was also essential in helping to commence the process of targeting HIV/AIDS experts from Uganda for formal interview. Focused discussions with HIV/AIDS experts in Geneva allowed the researcher to understand which Ugandan HIV/AIDS experts to target via email. It must be noted that a key gatekeeper was subsequently located within the Ugandan Ministry of Health (following discussions with experts within UNAIDS/WHO in Geneva). The researcher was then able to replicate the process of identifying additional participants for interview in person within Uganda.

#### *3.4.2 Role of semi-structured interviews with elites*

To generate data for analysis, semi-structured interviews with experts involved with the policy emergence of SGS and the analysis of Ugandan behavioural evidence used to advance explanations for the Ugandan HIV decline of the 1990s were conducted. Semi-structured interviewing is a well-established approach for generating qualitative data with its core features including an interactional exchange of dialogue, a relatively informal style and a thematic, topic-centered, narrative approach (Mason: 2002: pp. 62). An additional key feature of semi-structured interviewing relates to the notion of knowledge being contextual and situated, which requires the researcher to guarantee that relevant contexts are brought into focus so that situated knowledge can be produced (Mason: 2002: pp. 62).

Importantly, during the interview process understandings and meanings are created in an interaction, in essence a co-production, which involves the construction and reconstruction of knowledge (Mason: 2002: pp. 62). Semi-structured interviews can also be viewed as a social, or even a learning event, which have their own interactional rules wherein participants can discover, uncover or generate the rules of the game within the interview itself, whilst the interviewer can become more adept at interviewing, in relation to the techniques used to elicit responses (Holland & Ramazanoglu: 1994: pp. 135). The overarching motivation for using semi-structured interviews, as a method to generate data within this project, relates to the notion of flexibility. While acknowledging that it was my principal goal to elicit as much information about SGS, and the behavioural explanations accounting for the Ugandan HIV prevalence decline, it was important to allow the interviewees to talk from their own worldview via their own frames of reference, ideas and meanings that were familiar to them—and flexibility in the approach to interviewing was key to this taking place (Edwards & Holland: 2013: pp. 30). Noting the need to promote a flexible approach, each semi-structured interview was viewed, and conducted by the researcher, as a conversation with a purpose (Burgess: 1984: pp. 102) and it was attempted to make each interview a conversational partnership (Rubin & Rubin: 1995: pp. 10) rather than an asymmetric or top-down relationship.

In relation to this project, the researcher conducted interviews with elites in order to generate context-rich data which could facilitate the subsequent analysis of both SGS and the broader contestation surrounding the Ugandan HIV prevalence decline and the role of evidence in the development of global HIV prevention policy. Richards (1996) maintains that interviewing elites can permit researchers to discover valuable insights into their own perceptions and detailed understandings of political events (Richards: 1996: pp. 199). It is also reasoned that elite interviews can facilitate one's ability to capture information that is not officially recorded, and they can help researchers to interpret official documentation—particularly if one secures access to the authors responsible for putting together a relevant document or report (Richards: 1996: pp. 200).

Thus, by interviewing elites involved with the emergence of SGS and the analysis of data sources used to advance formative explanations for the Ugandan HIV prevalence decline it was possible for the researcher to unpack official narratives of SGS's development, to engage with the authors of official SGS policy documentation, and to explore the broader contestation of explanations for the Ugandan HIV decline of the 1990s. The table below outlines the names of the participants interviewed in the project, their employment title and the frequency/kind of interviews with each participant:

**Table 5: Participants interviewed within the research project**

<b>Participant name</b>	<b>Participant employment position</b>	<b>Frequency &amp; kind of interview with participant</b>
1. Dr Rand Stoneburner	Former GPA/UNAIDS epidemiologist	4 interviews (3 in person 1 via Skype)
2. Dr Txema Garcia-Calleja	Senior WHO epidemiologist	2 interviews (both in person)
3. Dr Elizabeth Pisani	Former UNAIDS consultant	1 interview (in person)
4. Former UNAIDS official	Former UNAIDS employee	3 interviews (2 in person 1 via Skype)
5. HIV/AIDS official within WHO	WHO employee	1 interview (in person)
6. Dr Michel Caraël	Former head of HIV prevention within UNAIDS	1 interview (in person)
7. Professor Manuel Carbello	Former head of behavioural research GPA	1 interview (in person)
8. Dr Stefano Lazzari	Former chair of the UNAIDS/WHO Working Group on Global HIV/AIDS/STI Surveillance	1 interview (via Skype)
9. Dr Mary Mahy	Monitoring & evaluation advisor UNAIDS	2 interviews (in person)
10. Professor Daniel Tarantola	Former senior employee of the GPA/former senior policy advisor to the Director General of the WHO	1 interview (in person)

11. Dr Daniel Low-Beer	Epidemiologist involved with the analysis of Uganda HIV surveillance data	1 interview (in person)
12. Dr Peter Ghys	Chief epidemiologist in the analysis division of UNAIDS	1 interview (in person)
13. Dr Wilford Kirungi	Senior epidemiologist Ugandan Ministry of Health	1 interview (in person)
14. Dr Elizabeth Madraa	Former manager Uganda's AIDS Control Programme	1 interview (in person)
15. Dr Zainab Akol	Manager of AIDS Control Programme, Uganda	1 interview (in person)
16. Dr Wolfgang Hladik	Epidemiologist Centers for Disease Control, Uganda	1 interview (in person)
18. Dr James Guwani	UNAIDS Strategic Information Advisor, Uganda	1 interview (in person)
19. Professor David Serwadda	Director of Institute of Public Health Makerere University	1 interview (in person)
20. Dr Frank Kaharuzza	Centers for Disease Control, Uganda	1 interview (in person)
21. Dr Alex Opio	Assistant Commissioner for National Disease Control, Uganda	1 interview (in person)
22. Professor Thomas Rehle	UNAIDS/WHO Consultant involved with the development of SGS	1 interview (via Skype)

In total, 29 semi-structured interviews were conducted with HIV/AIDS experts in Geneva and Uganda, with one interview being conducted in London at the Wellcome Trust and four interviews being conducted via Skype. The majority of the semi-structured interviews were conducted between August 2011 to February 2012. All but one of the interviews were conducted on a one-to-one basis, which was the approach the researcher sought to implement for each semi-structured interview. However, the first interview conducted during data collection ended up being more of a focus group—rather than a one-to-one interview (which was not planned or expected). During the first interview with Dr Txema Garcia-Calleja, other

HIV/AIDS experts (including Dr Mary Mahy and Dr Rand Stoneburner) were informed about my presence in the headquarters of UNAIDS. These HIV/AIDS experts subsequently entered the room, within which I was interviewing Dr Garcia-Calleja, and consequently were interviewed alongside Dr Garcia-Calleja. Naturally, this unexpected event changed the dynamics of the individual interview with Dr Garcia-Calleja. However, after explaining my need to interview participants in isolation, each expert agreed to be interviewed on their own at a future date.

### *3.4.3 Conducting the semi-structured interviews*

Acknowledging the importance of trust in generating valid data for analysis, time was always taken to introduce myself to the participants whilst explaining the goals of the research project and my research background prior to the interview taking place. Issues relating to informed consent, and the option of participants' comments being made anonymous, were also discussed – in detail – in advance of the interview commencing. Informed consent was obtained for every participant prior to the semi-structured interview taking place. 20 out of the 21 participants signed the consent form demonstrating that they were happy to be interviewed for this research, and that quotations could be directly attributed to them (see Appendix 1 for a copy of the project information sheet and consent form).

However, one participant, when signing the consent form in Geneva, listed a range of extra conditions relating to the use of their information within the research project. Owing to the complexity of their additional requests (namely their wish to review, and physical amend, the verbatim transcribed interview data prior to it being presented within the thesis) it was decided to not include any direct quotations from this participant with attribution. While this participant did tick the box stating that they were happy to be interviewed for this research, and that quotations could be directly attributed to them, their additional conditions (and their wish to amend their own data)



could have changed the meaning of the narratives generated within the context of the semi-structured interview.

To secure the informed consent with Dr Stefano Lazzari (who was the only participant the researcher did not meet in person), the consent form was emailed and signed by Dr Lazzari and a digital copy was emailed back to the researcher for safe keeping. Once informed consent was secured with Dr Lazzari, a Skype interview was conducted with the researcher in Geneva and Dr Lazzari in Tunis, Tunisia. Please note that informed consent with the other two participants interviewed via Skype had been secured in person during their principal interviews which took place in Geneva. Only one participant, who initially signed the consent form stating that they were happy to have quotations directly attributed to them changed their mind during data collection. During interview the participant stated that they were still happy to be interviewed (on the basis that all identifiable features were removed and that their participation in the research would not be disclosed). Thus, any identifiable features of this participant were removed in line with their request. Gaining informed consent was thus straightforward (as the vast majority of participants were happy to be interviewed and for their quotations to be directly attributed to them).

As a researcher, it was attempted to maintain a friendly and receptive demeanour whilst being sensitive to the needs of each participant. Being sensitive to, and acting upon, the individual needs of my participants was central prior to the interview taking place and it ensured that participants' questions, and their concerns, were addressed in order to facilitate an effective working partnership within the context of the semi-structured interview itself. In one instance a participant within UNAIDS was initially hesitant to be interviewed formally. However, after a careful discussion of my research aims (and an ice-breaking coffee in the UNAIDS cafeteria) it was possible to learn about the concerns of the participant and how best to address them prior to conducting the semi-structured interview.

Each interview commenced with questions that related to the historical development of SGS. In the interests of consistency, the following questions (or some variation of the questions below) were always asked at the start of each interview: Can you tell me how and why SGS came about?, Why did SGS come about?, Can you tell me why SGS was needed? These broad questions were posed in order to allow each participant to give me their distinct narratives, or oral histories, about the development of SGS and they were effective in opening up the discussion on my policy case study of interest. Questions were derived via document analysis – generally of key UNAIDS/WHO policy material which directly pertained to the development of SGS and its Ugandan evidence-base. Key UNAIDS/WHO documents (which were analysed prior to the commencement of the interviews taking place) allowed the researcher to formulate questions relating to the emergence of SGS, its evidence-base and the principal individual and institutions involved with its development. Key UNAIDS/WHO documents which were analysed to facilitate the development of questions asked during interview included:

- UNAIDS (1998a) Reaching regional consensus on improved behavioural and serosurveillance for HIV: Report for a regional conference in East Africa: UNAIDS Best Practice Collection. UNAIDS/98.9. Geneva. Available at: [http://data.unaids.org/publications/irc-pub04/una98-9\\_improvedsurveillance\\_en.pdf](http://data.unaids.org/publications/irc-pub04/una98-9_improvedsurveillance_en.pdf)
- UNAIDS (1998b) A Measure of success in Uganda: The value of monitoring both HIV prevalence and sexual behaviour, UNAIDS Case Study, UNAIDS Best Practice Collection. UNAIDS/98.8. Geneva. Available at: [http://www.unaids.org/en/resources/documents/1998/19980530\\_value\\_monitoring\\_uganda\\_en.pdf](http://www.unaids.org/en/resources/documents/1998/19980530_value_monitoring_uganda_en.pdf)
- UNAIDS/WHO (2000) Guidelines for Second Generation HIV Surveillance for HIV: The Next Decade. WHO/CDS/CSR/EDC/2000.5. Geneva. Available at: [http://www.who.int/hiv/pub/surveillance/en/cds\\_edc\\_2000\\_5.pdf](http://www.who.int/hiv/pub/surveillance/en/cds_edc_2000_5.pdf)

Interviews were carried out according to a semi-structured topic guide. However, it is important to note that the semi-structured interviews did not

follow a predesigned interview script as the researcher wanted the dialectic to evolve in an emergent and free-flowing manner (for a list of additional questions that were advanced during interview see Appendix 2).

During the interviews, reference was made to key UNAIDS/WHO policy documentation when discussing the historical development of SGS and the sources of evidence that were used to support its formal introduction in 2000. Indeed, when questions that related to the Ugandan sources of evidence used to support the development of SGS were given, hard copies of relevant UNAIDS/WHO policy documentation were made available for the participants to examine if necessary. Having these policy documents to hand during the interview was useful as it allowed certain participants to recall past events relating to the emergence of SGS and the creation of formative explanations for the Ugandan HIV prevalence decline of the 1990s—this potentially reduced retrospective recall issues. On occasion, handwritten notes were taken during the course of the semi-structured interviews to allow the researcher to return to key ideas or complex narratives that required further clarification. However, it was generally attempted to avoid taking notes during the interview as the researcher wanted to make clear that my full attention was given to the participants at all times.

#### *3.4.4 Tools used for data collection and the data transcription process*

Each interview conducted during data collection was audio recorded. Each audio recording was transcribed verbatim within 24 to 48 hours of the interview taking place. It was a self-imposed research rule to transcribe the interview data within this timeframe, as key points, key themes and interview nuance would otherwise have been overlooked or perhaps forgotten by the researcher. The level of transcription was highly detailed with pauses, coughs, hesitations and repetitions being transcribed. Transcribing the interview data was both labourious and time-consuming, however, in the process of transcribing the recorded interview data, the researcher started to gain much needed intimacy with the interview material

and rough patterns started to emerge from the interview data. Microsoft Word® 2008 was used to transcribe the audio files—each transcribed interview file was password protected to keep the interview data secure.

### 3.5 Approach adopted for data analysis

The researcher adopted an inductive approach to data analysis. Via the implementation of an inductive approach to data analysis, patterns, themes and categories emerge from the data rather than them being imposed on predefined categories or codes (Bradley et al: 2007: pp. 10). To organise the interview data, interview transcripts were reviewed, both in audio and written form, over a period of several months. By reviewing the interview data on multiple occasions it was possible to allow themes and patterns to emerge in a flexible manner. The role of iteration was key to the analytical approach implemented within this study. By revisiting the interview material on multiple occasions it was possible to make new connections and complex formulations in relation to what my data actually meant (Berkowitz: 1997: pp. 8). It is important to state that the role of iteration was not a simple mechanical task but a deeply reflexive process that was useful in developing insight and formal meaning (Srivastava & Hopwood: 2009: pp. 23). Immersion in the qualitative interview data for several months was essential in helping to develop themes, sub-themes and overarching narrative patterns. While the process of data immersion was both time consuming and isolating, it led to the development of defined findings that pertained to the historical development of SGS, and the contestation surrounding the Ugandan HIV prevalence decline of the 1990s. The physical procedure of data analysis within this study was highly tactile as interview transcripts were printed out, colour coordinated, cut into sections and displayed onto a results board. Hands-one intimacy with the interview data was important as it permitted the interview data to be physically organised which brought about a degree of visual clarity to this stage of the data analysis process.

Data were also coded during the analysis phase. Coding was used as it possesses several advantages when analysing qualitative data, namely, it fractures the data into smaller aspects, thus freeing the researcher from description and forcing interpretations to higher levels or abstraction, it is a pivotal operation for moving toward the discovery of core categories and it both follows up, and leads to, generative questions which can facilitate new insights and understandings (Strauss: 1987: pp. 134). The approach to coding was a highly inductive process, interview data were reviewed line-by-line and as a pattern in the data emerged a code was assigned. As the analysis developed, codes were continually assigned reflecting the themes that emerged from the interview data. As more data was analysed certain codes, that developed in the formative stages of data analysis, were adapted to reflect newer understandings of the interview data. The role of iteration was again key during the process of data coding in order to prevent the researcher from forcing preconceived results. Usefully, via the use of data coding overarching themes emerged from the interview data, which allowed the researcher to understand core aspects of the development of SGS and the identification of context-specific variables that appeared to shape the development of explanations for Uganda's contested HIV decline of the 1990s.

It was noted that qualitative data analysis software could have been used to organise and code my interview data—specifically Nvivo 11. Indeed, Nvivo 11 was initially tested in an attempt to assess its utility within the data analysis phase of the project. However, Nvivo 11 did not generate the intimacy that I needed as a researcher to analyse and thematically organise my qualitative interview data. In fact, when using Nvivo 11 I felt disconnected from the interview data and it was required to return to the methods outlined above. Key reasons for not using qualitative data analysis software are noted by Ulin et al (2005), and the following information resonates strongly with the data analysis process used within this study:

It is possible to conduct qualitative analysis without a computer. For many decades qualitative researchers have used handwritten notes or transcribed verbatim interviews by hand. They have

underlined text, written codes into pages margins, or otherwise highlighted segments of print to distinguish ideas and messages. They have cut and pasted, sorted, and piled – organizing data around central themes. In fact, some researchers still worry that relying too much on computer shortcuts will impede the process by distancing them from the text (Ulin et al: 2005: pp. 151).

Overall, the approach adopted for data analysis within this research project was based upon the notions of flexibility, induction and iteration. Via the systematic line-by-line analysis of the qualitative interview data over a period of several months, it was possible to allow key notions to emerge from the data itself rather than forcing out erroneous themes and findings.

### 3.6 Ugandan research clearance and University of Edinburgh ethical protocols

To undertake data collection within Uganda, it was legally required to submit an RS6 research clearance form to the Uganda National Council of Science and Technology (UNCST). UNCST is a semi-autonomous government agency that was created in 1990 to coordinate research and development activities within the country (UNCST: 2007: pp. 1). Once the RS6 was officially verified by UNCST, it was necessary for UNCST to inform the Office of the President that I wished to conduct research within the country. Once UNCST informed the President's Office about my research project, approval was granted from the President's Office. Having received approval from the Office of the President it was then required to report in person to the Resident District Commissioner within Kampala to show the appropriate letters of research approval from UNCST and the Office of the President (refer to Appendices 3 & 4 which display the letters of approval). Once the documentation was verified by the Regional District Commissioner within Kampala clearance to conduct my data collection within the country was formally granted.

This research project required a Level 2 University of Edinburgh SSPS ethical audit to be conducted. This project warranted a Level 2 ethical audit as it was

felt that participants could potentially be adversely affected by my research findings once publically disseminated. In light of this risk, relevant solutions were created to mitigate possible problems from developing. Indeed, a Level 2 ethical audit form was completed and relevant solutions were created to mitigate potential ethical dilemmas.

### 3.7 Epistemological and ontological reflections

While this research project is grounded within international public health policy, a transparent and reflexive approach to research necessitates that I outline my epistemological and ontological position. Although public health has traditionally been governed by epidemiological positivism and the desire to analyse reality through the rigorous application of a small range of quantitative techniques (Popay: 2003: pp. 59) the researcher does not subscribe to such positivist and reductionalist approaches. Indeed, the researcher adopts a post-positivist worldview subscribing to critical realism. Critical realism assumes the existence of a world that is independent of our perceptions of it (which echoes positivism), however, the world is accessible through our own subjectivity and senses (including those of the researcher – which echoes interpretative approaches). Those who adopt a critical realist worldview, are concerned with representing the structural order of the external, namely the social and the material world that underlies the experience of it, and they do not view scientific knowledge as the only means of accessing this order (Edwards & Holland: 2013 pp. 22). A critical realist epistemology is adopted by the researcher as it denies the idea that we can possess any ‘objective’ knowledge about the world around us and we must accept the possibility of alternative valid accounts of any study phenomena (Maxwell: 2012: pp. 5). Furthermore, critical realists subscribe to an ontological worldview in which a social world exists independent of our perceptions, whilst simultaneously accepting a form of epistemological constructivism—which contends that the world is inevitably constructed from our own standpoints and perspectives (Maxwell: 2012: pp. 5). Thus, critical realism rejects positivist epistemologies and the simple idea that

science can ‘get at truth’. In essence, the researcher is critical of our ability to understand reality and the adoption of a post-positivist epistemology allows the researcher to appreciate the fallibility of observation and the idea that knowledge construction itself is an imperfect process.

### 3.7.1 *Researcher reflexivity*

It is important to acknowledge that my individual perspectives, and my underlying epistemological position, will have influenced the collection and interpretation of the qualitative interview material created during the data collection phase of the study. While it is important to state that the interview data, which emerged during the semi-structured interviews, was co-constructed by the participant and the researcher, the actual process of data analysis was undertaken by the researcher in isolation. It is therefore important to discuss my reflexive nature to understand the potential influence that I had upon the qualitative data created within the research project itself.

During the course of this research project, the most critical issue that required regular reflection by the researcher, especially within the context of the semi-structured interviews, were my underlying beliefs about the role of evidence within the broader policymaking process. Importantly, my academic background (which is a *mélange* of political science and public health) initially led the researcher to possess strong normative opinions about how evidence *should* inform subsequent policy output in a directional and rational manner. Indeed, my original research project (as outlined above) sought to examine and critically assess evidence used to support the GBD estimates for HIV/AIDS within the context of Uganda (from an epidemiological worldview). It was my original wish to assess the ‘strength’ of the evidence used to support the development of the GBD estimates—whilst discussing the good and bad characteristics of the evidence itself. These notions gradually eroded as the direction of the project evolved and



my knowledge about the complexity surrounding the relationship between evidence and policy grew. However, at times during data collection and data analysis the researcher found it difficult to maintain a critical perspective on narratives from participants (or findings from data analysis) which illustrated that evidence used to support the development of SGS had been influenced by political and institutional factors. Indeed, the acknowledgement that evidence had moved within the policymaking process in a complex (or non-linear) manner was initially difficult for the researcher to comprehend as (according to my older worldview) the evidence supporting the development of SGS *should have moved* through the policymaking process in a logical and unproblematic manner (with good evidence informing policy and bad evidence being filtered out).

It was equally problematic to learn about the non-movement of evidence within the confines of the semi-structured interviews, as the views from my participants challenged my own underlying normative assumptions about the role of evidence within policymaking. However, critical reflection during the process of data transcription permitted the researcher to think more broadly about the role of evidence within policymaking and to work with, rather than against, the complex narratives that were advanced by my participants during the semi-structured interviews. Via a process of critical reflection, which took place during data collection, the researcher was able to adapt his old worldview pertaining to the use of evidence within the policymaking process, which therefore allowed the researcher to understand better the values and worldviews of my participants during data collection.

### 3.8 Methodological limitations

There are four key limitations pertaining to the methods used within this research project namely: limitations with the case-study method (in terms of data generalisability), the inability to locate, and analyse, two key sources of Ugandan evidence, which were used to support the development of SGS and to create formative explanations for the Ugandan HIV decline, problems

with gaining access to certain HIV/AIDS experts for interview—especially within UNAIDS and recall bias.

It must be noted that the case-study method has often been criticised for lacking scientific rigour and providing a small degree of generalisability—meaning that findings relating to the case study under analysis may not be transferable to other contexts (Crowe et al: 2011: pp. 7). It is also maintained by Yin (2009) that the greatest concern, in relation to the case study method, is the lack of rigour on the part of individual researchers (namely their inability to not follow systematic procedures or to allow equivocal evidence, or biased views, to influence the direction of findings and conclusions). An additional limitation of the case study method is that they take too long to implement and they often result in massive unreadable documents (Yin: 2009: pp. 15). Using a policy case-study (i.e. SGS) to examine how explanations advanced for the decline in Ugandan HIV prevalence were contested, and the role of evidence in the development of global HIV prevention policy will ultimately lead to the production of context-specific and esoteric findings. Thus, their wider generalisability in relation to the existing body of literature about the contested Uganda HIV prevalence decline maybe limited.

While attempts were made to locate relevant sources of documentary evidence pertaining to the development of SGS (in order to examine the broader Ugandan HIV prevalence decline and its contested nature), it must be noted that two key sources of evidence (which were cited within official UNAIDS documentation as being key to the introduction of SGS) could not be located for formal analysis. This must be acknowledged as a significant limitation. Within UNAIDS (1998a) it is claimed that two Ugandan population-based surveys of sexual behavioural change (conducted in 1989 and 1995) were used to demonstrate the value of behavioural surveillance data, and how this kind of data could be compared within serosurveillance data. Thus, these two population-based surveys were key in justifying the behavioural component of SGS—whilst concurrently providing sexual

behavioural change evidence that could help explain declining HIV trends within Uganda in the mid-1990s. These sources of evidence have been described by UNAIDS as “the best data so far” (UNAIDS: 1998a: pp. 5) and ‘centrepiece’ data which generated an idea of changes in current behaviour in various age groups in urban settings within Uganda (UNAIDS: 1998a: pp. 5).

Acknowledging the significance of the 1989 and 1995 population-based surveys of sexual behavioural change, as being key to the conceptual development of SGS, and formative explanations for the Ugandan HIV decline of the 1990s, careful searches to locate these sources of evidence were implemented. Despite online literature searching, bibliographic tracing and asking HIV/AIDS experts involved with the creation, and analysis of, these specific sources of evidence in person, it was not possible to locate these two sources of evidence which were seemingly key to SGS’s development (and to the creation of formative explanations of Uganda’s HIV seroprevalence decline of the early to mid-1990s). This is a significant limitation given the apparent centrality of these documents in relation to the development of SGS and formative explanations that could account for the Ugandan HIV seroprevalence decline of the 1990s.

Securing access to prospective participants, via the use of gatekeepers and snowball sampling, was not always successful in practice. While contact details of prospective participants were provided by gatekeepers within UNAIDS/WHO, certain prospective participants failed to reply to my requests to be formally interviewed. While emails were sent by the researcher to potential participants, certain individuals did not reply to my requests (which thus reduced the sample size within the study which is a limitation). While 29 HIV/AIDS experts were interviewed as part of this study, the absence of key policymakers consenting to be interviewed – especially within UNAIDS/WHO – has an effect upon the validity and broader generalisability of the empirical findings presented in the subsequent results chapters. While the data generated from the 29 interviews are of sufficient quality and quantity to make inferences about the Ugandan HIV decline, its contested nature, and the role of evidence in the

development of HIV prevention policy in the 1990s, the sample size of this study means that definitive statements relating to the aforementioned issues cannot be presented. While multiple attempts were made to interview HIV/AIDS experts and senior policymakers within UNAIDS/WHO to gain data for subsequent analysis, many individuals either declined to be interviewed – citing a lack of expertise – or they simply did not respond to my email requests.

It must be noted that the interview data generated within this study related to events from the mid to late-1990s. Therefore, it is appropriate to acknowledge that the empirical data generated within the study were subject to recall bias. This can undermine the internal validity of studies utilising self-reported data (Hassan: 2005: pp. 1). The researcher used physical print outs of UNAIDS/WHO policy documentation as a prompt to help interviewees to remember past events and previous actions. Although the recall of information depends entirely on human memory, which is inevitably imperfect and unreliable (Hassan: 2005: pp. 1), the combination of using policy documentation as a mental prompt and giving the participants time to reflect upon their life histories were useful techniques in an attempt to minimise this particular form of bias. It is also possible that some of the interviewees may have reinterpreted or selectively remembered events relating to the analysis of Ugandan behavioural evidence in the 1990s. This may be especially likely when these events have taken on particular significance for the person in question. Therefore it is important to acknowledge that the qualitative data generated within this project were subject to recall bias – especially in relation to the analysis and utilisation of Ugandan behavioural evidence in the 1990s.

### 3.9 Chapter summary

This chapter described the qualitative research design adopted within the project, the salience of the case study research method and how SGS was

located as a case study to examine how explanations advanced for the decline in Ugandan HIV prevalence were contested, and the role of evidence in the development of global HIV prevention policy. A detailed description of the semi-structured interviews was advanced, making clear the importance of gaining trust prior to the interview taking place, and the significance of flexibility during the interview process itself. The tools used for data collection and the approach adopted for data transcription was outlined, elucidating that the transcription process was highly detailed, with the process of transcription taking place within 24 – 48 hours of the interviews occurring. The approach adopted for data analysis was given, making clear that an inductive approach was taken to gain meaning from the qualitative interview data. The process of gaining UNCST research clearance and University of Edinburgh SSPS ethical protocols, that were addressed prior to the data collection phase were examined. The researchers' critical realist epistemological position was discussed, making clear the need to push away from epidemiological positivism and reductionalist worldviews when studying within the field of public health.

## CHAPTER FOUR: Examining the role of evidence in global HIV prevention policy development via the emergence of SGS and its evidence-base

### 4.1 Introduction to chapter

It was demonstrated in the introduction chapter that UNAIDS (1998a) framed the emergence of SGS as a problem-solving adaptation to older HIV surveillance approaches supported by Ugandan sexual behavioural change evidence. In fact, it was claimed by UNAIDS (1998a) that SGS emerged in reaction to the idea that behavioural surveillance data could be used to build upon older, serologically focused, HIV surveillance approaches in an ostensibly rational manner. UNAIDS (1998a) present SGS as having emerged at one specific event—namely a UNAIDS funded HIV surveillance consensus building workshop held in Nairobi, Kenya in 1997:

Surveillance systems appropriate in the early days of the [HIV] epidemic need to be adapted and built upon as our knowledge grows. UNAIDS sponsored the Nairobi workshop on improved surveillance with this in mind. The workshop succeeded in illustrating the potential for using behavioural data to interpret serological trends and in suggesting what countries might aim for in a “second generation” of surveillance activities (UNAIDS: 1998a: pp. 5).

Given the apparent centrality of the Nairobi workshop in the emergence of SGS and broader discussions relating to the development of HIV/AIDS prevention policy (via the analysis of Ugandan behavioural evidence presented at the workshop itself) this chapter aims to achieve two key objectives. First, to examine developments in global HIV prevention policy in the 1990s – particularly the introduction of SGS – including the role and use of evidence from Uganda in this policy. Second, to examine the Nairobi workshop in detail and to explore the underlying sources of evidence that were apparently drawn on to support the development of SGS itself. To

achieve this the chapter will examine the historical emergence of SGS in the 1990s and its evidence-base supported by interview material from HIV/AIDS experts who attended, or knew about, the workshop itself. Such examination is required to address aspects of the core aim of this thesis, namely to examine contested explanations for the decline in HIV prevalence in Uganda and the role of evidence in the development of global HIV prevention policy in the 1990s.

## 4.2 Examining the 1997 Nairobi Workshop

UNAIDS (1998a) claim that SGS emerged between the 10<sup>th</sup> – 13<sup>th</sup> of February 1997 at an HIV surveillance workshop held in Nairobi, Kenya (UNAIDS: 1998a: pp. 3). The workshop was presented as having been held to examine the strengths and weaknesses of existing HIV surveillance systems within the East African region in order to locate ways to enhance both serosurveillance and behavioural surveillance approaches respectively (UNAIDS: 1998a: pp. 3). Additionally, the workshop is described as having aimed to explore the links between behavioural surveillance and sentinel surveillance and to create cooperative links between epidemiologists and social scientists. It also sought to generate an East African dialogue focusing on enhancing HIV surveillance which would ensure UNAIDS support for the process (UNAIDS: 1998a: pp. 3). It is claimed that the workshop was attended by AIDS programme managers, government epidemiologists, specialists from UNAIDS, partner institutions and social scientists from Kenya, Malawi, Swaziland, Tanzania, Uganda, Zambia and Zimbabwe (UNAIDS: 1998a: pp. 3). The table below displays the individuals who attended the workshop, their institutional affiliation and their role at the workshop itself:

Table 6: Attendees of the workshop, their institutional affiliation and their role at the workshop itself

Institutional Affiliation	Attendee Name	Role at Workshop
1. UNAIDS Secretariat	Michel Caraël	Chair of workshop
2. UNAIDS Secretariat	James Carmichael	Technical input
3. UNAIDS Secretariat	Bernhard Schwartländer	Technical input
4. UNAIDS Secretariat	George Tembo	Technical input
5. UNAIDS	Tim Brown	Technical input
6. UNAIDS External Consultant	Elizabeth Pisani	Policy writer/input
7. USAID Senior Advisor	Barbara de Zalduondo	Technical input
8. USAID	Neen Alrutz	Technical input
9. Ugandan Ministry of Health	Godwil Asiimwe-Okiror	Technical input
10. Ugandan Ministry of Health	Joshua Musinguzi	Technical input
11. Ugandan Ministry of Health	Alex Opio	Technical input
12. Kenyan Ministry of Health	Godfrey Baltazar	Technical input
13. Kenyan Ministry of Health	Tom Mboya	Technical input
14. Malawian Ministry of Health	Owen Kaluwa	Technical input
15. Zambian Government	Rosemary Musonda	Technical input
16. Zambian Government	Moses Sichone	Technical input
17. US Census Bureau	Karen Stanecki	Technical input
18. US Census Bureau	Peter Way	Technical input
19. Harvard University	Daniel Tarantola	Technical input
20. International Center for Migration and Health	Rand Stoneburner	Technical input
21. University of Tromso, Norway	Knut Fylkesnes	Technical input
22. Medical Anthropologist	Tom Barton	Technical input
23. Tanzanian Government	Ephraim Kipuyo	Technical input
24. Tanzanian Government	Eustice Muhondwa	Technical input
25. Swaziland Government	R. Nxumalo	Technical input
26. Affiliation not determined	Omwany-Ojwok	Probable input
27. University of Heidelberg	Gabriele Riedner	Technical input
28. Affiliation not determined	C. Msuya	Probable input
29. Affiliation not determined	T. Zhuwa	Probable input
30. Affiliation not determined	Ruth Kornfield	Probable input
31. Affiliation not determined	Jaak Labeeuw	Probable input
32. Affiliation not determined	M. Kahindo	Probable input
33. Affiliation not determined	M. Bailey	Probable input



The table indicates that there were 33 attendees of the workshop. 6 attendees came from UNAIDS, with Michel Caraël, the former head of HIV prevention, taking the role of chairperson at the workshop itself. 2 attendees came from the United States Agency for International Development (USAID) with an additional 2 attendees coming from the US Census Bureau. 3 attendees came from the Ugandan Ministry of Health, 2 attendees came from the Kenyan Ministry of Health. 2 attendees came from Zambia, 2 from Tanzania and 1 from Swaziland. 5 attendees of the workshop came from HIC academic institutions or consultancy settings. 8 attendees also attended the workshop, providing technical and expert input relating to HIV/AIDS surveillance development at the workshop itself.

The theme of the centrality of the workshop, in relation to the formal development of SGS, was emphasised by the majority of the participants interviewed during data collection. Elizabeth Pisani, a former UNAIDS external consultant, described the workshop as the “crunch point” (Pisani: 31/8/2011) in relation to the development of SGS. This claim was reinforced by Daniel Tarantola, a former senior employee of the GPA/former senior policy advisor to the Director General of the WHO, who described the workshop as “important” to the formal development of SGS (Tarantola: 27/10/2011). Rand Stoneburner, a former GPA/UNAIDS epidemiologist, similarly claimed that the workshop was the “meeting where second generation surveillance evolved” (Stoneburner: 26/10/2011). The workshop was also described as the “main genesis” of SGS by Wilford Kirungi, a senior epidemiologist from the Ugandan Ministry of Health. Joshua Musinguzi, the control programme manager of HIV/AIDS within the Ugandan Ministry of Health, claimed that the workshop as “an open meeting where we [Ugandan Ministry of Health] presented our surveys...we presented our antenatal clinic data” (Musinguzi: 27/01/2012). Musinguzi also asserted that the workshop was an opportunity for attendees to:

Throw issues on the table...then in subsequent discussions and in the group work...that’s when people were beginning to come up with, how we move this [SGS] forward to have an approach

that is systematic...that puts things together in protocols that can help countries go back and collect data (Musinguzi: 27/01/2012).

However, a contradictory narrative about the function of the workshop, in relation to the development of SGS, was advanced by Michel Caraël, former head of HIV prevention within UNAIDS and chairperson of the workshop itself:

I wouldn't overemphasise the workshop. For sure, the workshop is one point where you put everybody together...but it is not the workshop who [sic] convinced the people. The people were convinced before the workshop (Caraël: 20/09/2011).

This narrative is incongruous as it appears to be inconsistent with the majority of interviewees who highlighted the significance of the workshop in helping develop SGS. It also appears to contradict official UNAIDS accounts that describe the historical development of SGS (as UNAIDS policy literature states that SGS formally emerged at the workshop itself). Given the significance of Michel Caraël at the workshop, and his function as head of HIV prevention within UNAIDS at the time of the workshop, it is interesting to discover that he appears to promote the idea that the development of SGS perhaps occurred at an earlier point in time.

#### 4.3 Examining the structure of the 1997 Nairobi workshop

The workshop commenced by analysing a Ugandan case study presentation which was given by Ministry of Health officials from the Ugandan Government (UNAIDS: 1998a: pp. 3). Those presenting at this stage of the workshop included: Joshua Musinguzi, Alex Opio and Godwil Asiimwe-Okiror who were epidemiologists and senior HIV / AIDS specialists from the Ugandan Ministry of Health. The role of Ugandan HIV surveillance data presented at the workshop was highlighted by Joshua Musinguzi, the control programme manager of HIV / AIDS within the Ugandan Ministry of Health, who described the manner in which Uganda's HIV prevalence data, which indicated a decline in HIV infection, were discussed at the workshop:

...that is when the meeting in Nairobi was organised and as a country we thought it would be helpful for us [Ugandan Ministry of Health officials] to go and present. And I think at that time...there were very few countries...if not only us [Uganda] in this region who were observing declining [HIV] trends. So our presentation was especially interesting for many other countries where the [HIV] epidemic was either stable or actually rising (Musinguzi: 27/01/2012).

The notion of declining HIV trends emerging from the Ugandan surveillance data was claimed to be an object of tremendous excitement at the workshop by Musinguzi:

Even in the presentation we had in Nairobi there was a lot of excitement. For the first time in an African country we are seeing something...some kind of impact on the [HIV] epidemic. Whether that's because of the behaviour, whether it was because of the natural trend of the [HIV] epidemic...but at least we were seeing something and it was so exciting...it was very exciting. And I think it drove momentum further for everybody to see...let's understand the dynamics...the drive for second generation was really strong after those presentations...especially after our [Ugandan Ministry of Health] presentation (Musinguzi: 27/01/2012).

Once the presentation and analysis of the Ugandan surveillance data was complete, other presentations from the aforementioned participant East African countries were given. UNAIDS (1998a) does not directly state which countries gave presentations after the Ugandan case study was outlined. However, it is likely that subsequent country presentations were given by attendees from: Kenya, Malawi, Tanzania, Swaziland and Zimbabwe. The only other country which is directly cited within UNAIDS policy documentation, in terms of presenting HIV surveillance data at the workshop, is Zambia.

According to UNAIDS (1998a) data from Zambia, produced by Knut Fylkesnes<sup>5</sup> were presented at the workshop. This study presented

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<sup>5</sup> Fylkesnes, K. (1998) The first Zambian population-based HIV survey: saliva-based testing is accurate and acceptable, *AIDS*, Vol. 26, No. 5, pp. 540 – 541.

information which compared sentinel surveillance data with results from a survey of HIV prevalence within the general population (UNAIDS: 1998a: pp. 10). Importantly, the HIV prevalence data presented within this study, after discussion in the workshop were re-analysed by single year of age (UNAIDS: 1998a: pp. 11). This, at the time, novel year-by-year analysis of surveillance data departed from the traditional approach of presenting HIV prevalence data aggregated by five-year age groups. By examining HIV prevalence data by single year of age, their analysis illustrated the importance of “gathering behavioural data, rather than jumping to conclusions about behaviour from purely epidemiological evidence” (UNAIDS: 1998a: pp. 12).

This conclusion was arrived at as the previous surveillance data analysis, which had been analysed according to traditional five-year age groups, gave misleading indications of behavioural change in the youngest age cohorts. UNAIDS (1998a) also claim that the Zambian data presented at the workshop validated “the crucial importance of looking at data by single year of age if we are to understand trends in infection” (UNAIDS: 1998a: pp. 12). The role of Zambian data presented at the workshop was also emphasised by Elizabeth Pisani, a former UNAIDS external consultant:

We sat in that meeting [Nairobi] and we farted around with different data sets that were available...which were not very many. One of the people who was there was Knut [Fylkesnes] who was working at that time in Zambia. And he had the raw data set with him...their surveillance data. So we all sat there and said well what if we could look at younger age groups...different from older age groups (Pisani: 31/08/2011).

Pisani then claimed that the aforementioned Zambian data were re-analysed overnight during the course of the workshop by Knut Fylkesnes:

And then we all went out and drank very heavily...and had a very funny dinner...and then the next morning...Knut [Fylkesnes] was really excited because he stayed up all night reanalysing his data...and showed that there were distinct differences in trends by age...so that gives you an indication of what was happening (Pisani: 31/8/2011).

Pisani's narrative, consistent with UNAIDS policy documentation, suggests that Zambian data appear to have played a role in helping to justify the need to integrate behavioural surveillance data alongside serological surveillance to improve established HIV surveillance approaches and broader HIV prevention policy. Once the Ugandan and Zambian presentations were complete, the attendees of the workshop spilt into two groups to work on improvements in behavioural and serosurveillance systems respectively (UNAIDS: 1998a: pp. 3). Following the group work, a plenary session was held which presented the recommendations generated during the group work. The recommendations that were voiced at the plenary session "became the departure point for country working groups" (UNAIDS: 1998a: pp. 3). After the plenary session, epidemiologists and social scientists from the participating countries worked together on country specific plans, synthesising the recommendations on improving HIV surveillance created by themselves and their colleagues throughout the duration of the workshop (UNAIDS: 1998a: pp. 3). Following the country presentations, group work and plenary discussions six outcomes of the workshop were formally advanced within subsequent UNAIDS best practice guidelines. The six key outcomes of the workshop included:

- The establishment of the major components of second-generation systems;
- The successful identification of major limitations in current HIV surveillance systems;
- The creation of recommendations to enhance existing systems in certain areas of monitoring and data collection;
- Illustrated the significance of collecting behavioural data to inform epidemiological data;

- Catalysed action plans for synthesising the conclusion of the Nairobi workshop into domestic surveillance activities;
- Helped to build up effective partnerships between behavioural scientists and epidemiologists within the East African region (UNAIDS: 1998a: pp. 12).

UNAIDS (1998a) finally claims that it formulated guidelines for SGS as a direct outcome of the workshop itself:

As a consequence of the workshop, UNAIDS has already formulated guidelines for second-generation surveillance. These will cover recommendations for sentinel serosurveillance and behavioural surveillance, and will be made available to all countries (UNAIDS: 1998a: pp. 12).

Having examined the internal structure of the workshop, it is now important to explore the evidence used to support the policy development of SGS in greater detail. This is required to determine which sources of evidence were used to support the development of SGS, and to understand if the claims surrounding the significance of its Ugandan evidence-base, as advanced by UNAIDS (1998a; 1998b), are fully comprehensive.

#### 4.4 Mapping out the evidence supporting the development of SGS—competing narratives from interviewees

A range of competing narratives were provided by interviewees relating to the sources of evidence used to support the development of SGS and where they emanated from. Four themes were identified in relation to the evidence used to support the introduction of SGS. First, the theme that older HIV surveillance data, produced during the time of WHO's GPA, were used to support SGS. Second, the role of Ugandan evidence and the development of SGS, which is broadly congruent with existing UNAIDS policy literature. Third, the theme that Ugandan evidence was not relevant to the

development of SGS—which appears to contradict UNAIDS policy documentation. Fourth, the role of other sources of sexual behavioural evidence, namely data that emerged from the HIV/AIDS epidemic in the United States in the 1980s onwards, and its association with the development of SGS. In the process of examining the evidence used to support the introduction of SGS, the following four sections will also begin to introduce key individuals (namely HIV/AIDS experts) involved with the development of SGS and broader global HIV prevention policy—they are described in order to gain formative understandings of who did what and when in relation to SGS and HIV/AIDS policy development in the 1990s. However, it must be noted that the evidence mapping within the following four sections, and the identification of relevant HIV/AIDS experts involved with the development of SGS and broader HIV/AIDS policy development, serves a mainly descriptive purpose, namely, to allow this chapter to ascertain who did what on the basis of which sources of evidence in relation to SGS. Such description will allow subsequent chapters to understand better the role of evidence used to support the introduction of SGS, the key HIV/AIDS experts involved the analysis of SGS's evidence-base and the development of HIV/AIDS prevention policy in the 1990s.

#### *4.4.1 Long-term GPA evidence and the development of SGS*

The first theme relates to long-term GPA surveillance data sources being referred to as evidence to support the development of SGS. Txema Garcia-Calleja, a senior epidemiologist from WHO, claimed that multiple sources of evidence from GPA were used to support the development of SGS. Garcia-Calleja asserted that the evidentiary basis for SGS can be traced back to early behavioural surveillance surveys that were created by GPA in the early 1990s:

There were a lot of data...I mean what happened is in the 1990s the Global Programme on AIDS started promoting national behavioural surveys and they had a big database (Garcia-Calleja: 05/08/2011).

Garcia-Calleja also named individual decision-makers who were involved with early GPA behavioural surveys conducted in the 1990s, which included Daniel Low-Beer and Rand Stoneburner who were former GPA employees:

There was Daniel Low-Beer...there was also Rand Stoneburner involved with [HIV] surveillance data...and Rand [Stoneburner] use to work with and Daniel [Low-Beer] with the Global Programme of AIDS in the 1990s (Garcia-Calleja: 05/08/2011).

The role of Michel Caraël in relation to GPA surveillance data sources, which helped support the development of SGS, was also emphasised by Garcia-Calleja:

...the 1990s the Global Programme on AIDS it was with Michel Caraël...he's another former WHO/UNAIDS colleague...they were promoting national household behavioural surveys it was funded by the Global Programme on AIDS...national behavioural surveys...only about HIV/AIDS. So it was lots of countries...lots of data and there are several papers by Michel Caraël about these results in different surveys (Garcia-Calleja: 05/08/2011).

Echoing the above claim, a former UNAIDS official contends that evidence supporting the introduction of SGS came about from "a number of papers by Michel Caraël" (former UNAIDS official: 25/10/2011). These papers, which were created by Michel Caraël whilst working within the GPA, showed that behavioural surveillance approaches could be used to understand better the behavioural drivers of HIV transmission which, in turn, could be used to aid the development of wider HIV/AIDS prevention policy:

I think you have a number of papers by Michel Caraël...because I read all these papers...and there was more and more evidence that if you had safer behaviours that it was going to reduce [HIV] incidence (former UNAIDS official: 25/10/2011).

Michel Caraël, the former head of HIV prevention within UNAIDS, also claimed that previous GPA surveillance studies created in the early 1990s were used to show the utility of behavioural surveillance:



I think to me it [evidence for SGS] came out in very early in the early 1990s...where I was in WHO...in the Global Programme on AIDS. And we [GPA] were trying to look at the diversity on sexual behaviour. I was in a research unit...and we would launch...what we called the comparative population survey...about sexual behaviour and we started to develop an analysis of risk behaviours for HIV...associated with sexual behaviour. So from there, I got the impression that despite many biases in the reporting in sexual behaviour...there was a possibility to record this type of data (Caraël: 20/09/2011).

#### *4.4.2 Ugandan evidence and the development of SGS*

A second theme relates to the role of Ugandan evidence used to support the development of SGS. Manuel Carbello, the former chief of behavioural research at the GPA maintains that an analysis of Ugandan data conducted by Rand Stoneburner, a former GPA/UNAIDS epidemiologist, were relevant sources of evidence that supported the development of SGS:

Rand [Stoneburner] has done a lot of work...for example with Uganda data and I think that Rand [Stoneburner] would be among the first to say that if we had taken the Uganda...for example Rakai data...and then the Kampala and Entebbe data at face value it wouldn't have told us anything about who was getting the message...and what interventions were beginning to work. And I think that Rand's data analysis basically showed that the number of new cases of HIV was indeed coming down...but only in selected groups (Carbello: 20/09/2011).

Rand Stoneburner, a former GPA/UNAIDS epidemiologist, also emphasised the centrality of Ugandan data relating to the development of SGS and broader HIV prevention policy development. Stoneburner noted that two population-based sexual behavioural surveys conducted in 1989 and 1995 were used to understand sexual behavioural change within the country. Stoneburner maintained that these behavioural data sources from Uganda helped to assemble the SGS approach from the mid-1990s onwards "second generation surveillance kind of started with what was cobbled together within Uganda" (Stoneburner: 05/08/2011). Stoneburner also commented on the seemingly intuitive nature of using the 1989 and 1995 Ugandan

behavioural surveys to help improve older, serologically focused, HIV surveillance approaches:

...we have these [1989 and 1995] behavioural surveys...let's put them together...wasn't that interesting. It wasn't a policy...let's do second generation surveillance investigators already said well we have this data...of course it's reasonable let's just look at them (Stoneburner: 05/08/2011).

Building upon his earlier GPA evidence narrative, Txema Garcia-Calleja, a senior epidemiologist from WHO, also highlighted the central role of Ugandan behavioural data in developing the SGS approach. Data below illustrate the manner in which different decision-makers sought to use Ugandan data to improve older HIV surveillance methodological approaches:

But the highlight was Uganda because there was a declining [HIV] prevalence...and changes in sexual behaviour...and Daniel Low-Beer and Rand Stoneburner...they were involved with the analysis of the data. And then Elizabeth [Pisani] and Bernhard [Schwartländer] they used this as an example...to look at it from different sources...and they kind of knew the idea of...okay lets promote [HIV] surveillance again and lets try to pull up together...not only HIV prevalence...but...as I say with other parameters (Garcia-Calleja: 05/08/2011).

The central role of Ugandan data was also asserted within UNAIDS policy documentation (UNAIDS: 1998a; UNAIDS: 1998b). Within: 'Reaching Regional Consensus on Improved Behavioural and Serosurveillance for HIV – Report from a Regional Conference in East Africa' (UNAIDS Best Practice Collection Key Material: 1998) a subsection named "the best data so far" (UNAIDS: 1998a: pp. 5) mentions that "centrepiece" (UNAIDS: 1998a pp. 5) data presented at the workshop emanated from urban areas in Uganda where a significant decrease in HIV prevalence had been recorded, especially in younger age groups (UNAIDS: 1998a pp. 5). Reference is also made to an earlier UNAIDS study named: 'A Measure of Success in Uganda' (1998b) which remains part of UNAIDS' Best Practice Collection. This earlier UNAIDS document was purported to demonstrate "a plausible link between the epidemiological data showing declining HIV prevalence in urban areas

and behavioural data showing growing adoption of safer sex among youths” (UNAIDS: 1998b: pp. 12). This earlier UNAIDS study was therefore important in providing support for linking behaviour change data with serological data sources and in understanding the sexual behavioural change reasons that could account for the Ugandan HIV prevalence decline. The UNAIDS (1998a) report also claims that Ugandan Ministry of Health officials, attending the workshop were able to make reference to two population-based surveys on sexual behavioural change from 1989 and 1995. These studies “gave an idea of changes in current behaviour in various age groups in urban settings” (UNAIDS: 1998a: pp. 5).

These two 1989 and 1995 population-based Ugandan surveys were presented alongside “evidence compiled from more than 300 smaller-scale sociological studies” (UNAIDS: 1998a pp. 5) which strongly suggested “a rise in the age at first sex and more use of condoms in cities” (UNAIDS: 1998a pp. 5). The 300 smaller-scale sociological studies were described as having been reviewed by Tom Barton, an anthropologist, under the direct instruction of Michel Caraël, the former head of HIV prevention within UNAIDS and the chair of the workshop. During interview, Michel Caraël commented on the manner in which he instructed Tom Barton to conduct the review of the Ugandan studies:

I was the one who contacted [Tom] Barton...who was a friend at the time. He reviewed not 300 but probably 150 a very light review I should say...it was useful showing...a lot of studies...really captured in Uganda...you know? Showing some evidence of behavioural change there (Caraël: 20/09/2011).

However, the 300 small-scale sociological surveys reviewed by anthropologist Tom Barton, under the instruction of Michel Caraël, appears to be a contested and complex issue. The following data begin to introduce the complexity:

*Interviewer: I would really appreciate if I could try and find those 300 sociological studies that were used for the Measure of success in Uganda...the 1997/1998...*

Michel Caraël: Okay...there was a conflict there because we were in conflict with Rand Stoneburner with this journalist...who is linked to Daniel Halperin...what is her name? Who wrote on Uganda...

*Interviewer: Helen Epstein?*

Michel Caraël: Helen Epstein...is really somebody dishonest. I mean that...I wouldn't trust [her] for anything...I mean...she was accusing me of having deleted the conclusion of [Tom] Barton...because it wouldn't meet my expectations...let's say or something like that...because I was...she said...promoting condom use despite the evidence that condom use were [sic] not working...so for me it's like rewriting the history again (Caraël: 20/09/2011).

It was also claimed by Rand Stoneburner, a former senior GPA/UNAIDS epidemiologist, that there were "misadventures" (Stoneburner: 05/08/2011) in relation to the Ugandan behavioural data that were used to develop the SGS approach and to gain formative understandings of the Ugandan HIV prevalence decline at the workshop:

They [UNAIDS] were moving to second generation...I was at the meeting in Nairobi and yeah it was a great foundation for building it...but when you talk about Uganda there were some misadventures let's say (Stoneburner: 05/08/2011).

Elizabeth Pisani, a former UNAIDS external consultant, also advanced a complex narrative which relates to Uganda's HIV prevalence decline 'success' story. Data advanced by Pisani suggest that there were issues between certain individual decision-makers relating to the sexual behavioural change reasons contributing to Uganda's HIV 'success' story:

I don't know what Rand [Stoneburner] told you...but the reason that so much effort was put into that [explaining HIV decline within Uganda] was partly because there was a catfight going on. So Uganda was a success story...we declared it a success story...we have declared it as a success...so now why is it a success? So there's a giant catfight going on about why it succeeded (Pisani: 31/08/2011).

In the process of explaining this “catfight” (Pisani: 31/08/2011) amongst decision-makers, Pisani advanced the names of decision-makers who were involved with interpreting the emerging HIV decline narrative, and the behavioural change reasons contributing to the HIV decline itself within Uganda:

So this guy called...what’s his name...Green? He’s completely loopy...anyway he decided that it was because of more abstinence...because of a rise in age at first sex in Uganda...that’s what explained it. And then Rand [Stoneburner] decided that it was partly about...they were proving that it’s about abstinence...and that it was about partner reduction...and so we felt the need to prove that it was about condoms...and it was a stupid, stupid, stupid catfight which actually just took up an awful lot of time and energy...and everyone was just pissing on one another’s patch (Pisani: 31/08/2011).

The data above are beginning to highlight that there is a degree of complexity relating to Ugandan behavioural data sources used to support the development of SGS which is interlinked with an overarching narrative, specifically the process of understanding which specific sexual behavioural change reasons were contributing to declining HIV prevalence rates within the country. These contested narratives which relate to “conflict” (Caraël: 20/09/2011) and “misadventures” (Stoneburner: 05/08/2011) will be explored in greater analytical detail in the two following results chapters (as it is the function of this chapter to describe and introduce the actual sources of evidence used to support the development of SGS itself). Having outlined the role of Ugandan evidence in supporting the introduction of SGS, which appears to be a contested issue, it is now appropriate to introduce other themes relating to the evidence used to support the development of SGS itself. This is undertaken to demonstrate a greater level of complexity surrounding the evidence used to support the development of SGS, and the finding that Ugandan evidence may not have been as central to SGS’s introduction (which thus appears to contradict aspects of the narratives above and existing UNAIDS policy literature).

#### *4.4.3 Ugandan evidence not being relevant to the development of SGS*

It was claimed by Elizabeth Pisani, a former UNAIDS external consultant, that data from Uganda were not central to the introduction of SGS “we didn’t even look at it” (Pisani: 31/08/2011). Pisani maintains that Ugandan HIV surveillance data were of poor quality which resulted in the data not being used to inform the development of SGS:

I see a lot of shit data sets...and that was a shit data set. There was no codebook...there was no...we can’t even find the base questionnaire that was used...we [UNAIDS] are making assumptions up the wazoo about the comparability of individual variables (Pisani: 31/08/2011).

However, Pisani’s doctoral thesis interestingly contrasts with her aforementioned narrative which appears to highlight the principal role of Ugandan behavioural data and its relationship with developing SGS at the workshop:

A meeting called to review the evidence in Nairobi in February 1997 looked carefully at a number of behavioural studies in Uganda (principally nationally-representative cross-sectional surveys of sexual behaviour conducted in 1989 and 1995)...The meeting concluded that a reduction in risk behaviour was likely to have contributed to a real reduction in HIV prevalence among young Ugandans (Asiimwe-Okiror, Opio et al. 1997; UNAIDS 1998). It also led to preliminary recommendations for wholesale changes to national HIV surveillance systems, described below (UNAIDS 1998). It was at that meeting that we first used the term “Second Generation Surveillance” to describe the systems that were emerging as the new model” (Pisani: 2006: pp. 26 – 27).

Pisani also made reference to the 300 small-scale sociological surveys reviewed by Tom Barton, which as demonstrated above, appears to be a problematic issue according to Michel Caraël, the chair of the workshop and former head of HIV prevention within UNAIDS. Prior to meeting Elizabeth Pisani for interview, emails were sent in an attempt to locate the aforementioned 300 small-scale sociological studies that feature within the UNAIDS official policy documentation for critical appraisal. In asking her where and how the 300 studies were conducted Pisani commented:

Re the 300 studies: You don't really believe we took 300 studies into account, do you? We say all sorts of things post hoc to support the decisions we make, but most are made on sparse data and for largely political reasons. Though the politics was not that pronounced in the SGS process, the policy was based almost exclusively on the Ugandan sentinel data and Knut's Zambian study, plus a desperate need to move away from pregnant women in countries where most infections are in men (Email from Elizabeth Pisani: 08/04/2011).

In a subsequent email exchange intending to clarify the significance of the 300 small-scale Ugandan sociological studies, which are cited as evidence within official UNAIDS documentation, Pisani reiterated her scepticism about their relevance and substance:

I honestly think you are giving these mystical/mythical 300 studies far too much importance. As far as I know, the only way they "underpinned" SGS was that Tom [Barton] made a presentation mentioning that he'd look at a lot of studies, and we wrote down in a report that we had lots of evidence for something that we decided to do on the basis of two days sitting in a room, and quite a few beers on a terrace. And since it was me that wrote the second generation surveillance guidelines, as far as I know is probably as far as anyone knows (Email from Elizabeth Pisani: 21/04/2011).

The contradictory narratives advanced by Pisani, and the claim that Ugandan data sources were not used to support the development of SGS (due to their inadequate empirical quality) indicate that she had contrasting understandings about the function and value of Ugandan evidence in supporting SGS's development. It also appears that Pisani's conceptualisation, regarding the evidence used to support the development of SGS is unclear, as contradictory accounts have been advanced in her doctoral thesis and by her via email.

#### *4.4.4 New York behavioural data and Demographic Health Survey data and the development of SGS*

A distinct theme relating to the evidence used to support SGS was also advanced by Rand Stoneburner, a former GPA/UNAIDS epidemiologist, who claimed that the evidentiary basis for SGS had a long-term time frame which goes back to the HIV epidemic emerging in gay men in HICs from the late-1980s onwards. Stoneburner noted that behavioural surveys on sexual behaviour conducted in New York in the 1980s initially provided evidence that behavioural data could be used to understand the transmission of HIV in specific at risk groups:

To do a behavioural survey was a pretty radical idea back then we had some in New York...we did a population survey but most of them were done in special risk groups (Stoneburner: 26/10/2011).

Stoneburner also remarked that the idea for using behavioural surveys, which was the key idea proposed at the workshop, had been implemented in New York City nine years earlier:

I mean we did the first behavioural survey in New York City in 1988/89 and we didn't call it second generation surveillance (Stoneburner: 26/10/2011).

An additional standalone theme was advanced by Mary Mahy, a monitoring and evaluation advisor from UNAIDS, who claimed that other behavioural data sources supported the introduction SGS. Mahy claimed that data from Demographic Health Surveys (DHS), and other large-scale household surveys conducted within the field of reproductive health, showed the benefits of conducting behavioural surveillance in addition to serosurveillance. These studies conducted in the mid to late-1990s were another source of data used to demonstrate the value of including behavioural data to enhance older approaches to HIV surveillance, and to generate more information that could be used to inform the development of subsequent HIV/AIDS prevention policy:



If you go to reproductive health stuff you have to collect data on behaviour in order to understand any behavioural changes...and so I think the DHS's before...a lot of the data collected on maternal child health happened to be...it was fertility related...so it was when did you start having sex and those sorts of things. So those questions then could be used to understand what was going on with the HIV epidemic. So it was just a really natural progression...like okay where's more data, where's more data...and you sort of go into the DHS and other household surveys that were for reproductive health...but gave you answers for HIV as well (Mahy: 23/09/2011).

The four sub-sections above have presented an array of heterogeneous claims about the evidence used to support the formal development of SGS. It is significant to note that the findings appear to suggest that different decision-makers, involved with the development of SGS, and more broadly HIV prevention policy, possessed different conceptualisations about the actual evidence used to support SGS's introduction in the year 2000. The findings above are significant as they appear to contradict the recorded sources of evidence used to support the development of SGS, as advanced by UNAIDS within its official policy documentation (UNAIDS: 1998a). Equally, the findings outlined above appear to indicate that Ugandan sexual behavioural change evidence, presented at the workshop, are contested as certain HIV/AIDS experts debated the sexual behavioural change reasons that contributed towards Uganda's HIV decline of the early to mid-1990s. Having examined the evidence used to support the introduction of SGS, it is now required to examine why SGS was formally introduced by UNAIDS/WHO in the year 2000. Doing this will enable the chapter to understand better the evolution of SGS and it will facilitate subsequent chapters to provide a more comprehensive account about the function of evidence used to support the introduction of SGS itself and the development of broader HIV/AIDS prevention policy in the 1990s.

## 4.5 Exploring the development of SGS an examination of narrow and broad reasons

This section examines the reasons that contributed towards the formal development of SGS by UNAIDS/WHO in the year 2000. It is organised into narrow and broad reasons that emerged during data analysis. Narrow reasons relate to the need for SGS to improve older HIV surveillance approaches via the integration, and triangulation of, multiple data sources (which is mainly congruent with existing UNAIDS/WHO policy documentation). Whereas, broad reasons relate to the need for SGS to function as a marketing tool to help UNAIDS gain institutional credibility in developing an effective approach to global HIV surveillance policy (that could be used by countries to address the global HIV/AIDS epidemic more efficiently). An additional broad reason relates to the function of SGS to bridge socio-behavioural and epidemiological disciplinary approaches (and decision-makers from both disciplines) together when UNAIDS was launched in 1996. Interview data suggest that there was general consensus surrounding the narrow reasons that contributed towards the formal introduction of SGS in the year 2000. Four specific themes emerged in relation to the narrow reasons that led to the introduction of SGS. First, the theme of increasing the number and type of surveillance data sources to improve older approaches to HIV surveillance. Second, the theme of integrating behavioural data with existing serological data sources to facilitate the process of data triangulation. Third, the need for SGS to permit decision-makers to understand better the structural, or sociological factors, that influence patterns of HIV infection. Forth, the need for SGS to shift older HIV surveillance approaches away from AIDS case reporting as this kind of data did not give decision-makers up-to-date information about the evolution of the HIV epidemic. Each of these themes will now be examined in the order outlined above.

The theme of increasing the number and type of surveillance data sources was raised by Peter Ghys, chief epidemiologist within the analysis division

of UNAIDS. Ghys claimed that SGS emerged as earlier HIV surveillance guidelines were “quite simple” (Ghys: 06/12/2011) which possessed “limited content suggestions” (Ghys: 06/12/2011) therefore “different sources of data” (Ghys: 06/12/2011) were integrated to provide “more insight into the [HIV/AIDS] epidemic and its trends” (Ghys: 06/12/2011). This theme was echoed by an HIV/AIDS official within the WHO, claiming that SGS emerged having realised that the global HIV/AIDS pandemic was behaving in a very diverse manner, which required multiple sources of data to be triangulated to understand better ongoing HIV prevalence and incidence trends (HIV/AIDS official within the WHO). Stefano Lazzari, former chair of the UNAIDS/WHO Working Group on Global HIV/AIDS/STI Surveillance, claimed that SGS was developed as HIV/AIDS surveillance experts realised that serologically focused HIV surveillance systems generated a “late and incomplete epidemiological picture” (Lazzari: 21/09/2011). SGS was therefore developed for data improvement and to make ongoing epidemiological information emanating from HIV surveillance systems more complete and up-to-date. Focusing on increasing the number of surveillance data sources, Frank Kaharuza, from CDC Uganda, claimed that older HIV surveillance approaches were “inadequate” (Kaharuza: 13/02/2012) noting that SGS was important in understanding the need to “use all your data...and to use multiple data sources” (Kaharuza: 13/02/2012). Emphasising data improvement and increasing the number of HIV surveillance data sources, Elizabeth Madraa, the former manager of Uganda’s AIDS Control Programme, claimed SGS was developed:

To improve the quality of the data in HIV...the previous HIV data was just being collected...just using the mothers from sentinel sites (Madraa: 20/01/2012).

Madraa also claimed SGS was needed “to improve the quality of the data collected on HIV and AIDS” (Madraa: 20/01/2012). One former UNAIDS official claimed that SGS was developed to integrate multiple types of surveillance data, which had formerly been analysed in a state of isolation into a unified framework “it [SGS] brings together HIV seroprevalence data,

behavioural surveillance and AIDS mortality data together” (former UNAIDS official: 25/10/2011).

A second theme relates to older HIV surveillance approaches lacking behavioural data sources which could, if triangulated<sup>6</sup> with existing serological prevalence data, be used to understand better variations in the evolving HIV epidemic. Incorporating “behavioural surveillance side by side with biological surveillance” (Kirungi: 19/01/2012) was a key data improvement need which could help “increase the explanatory power” (Kirungi: 19/01/2012) of older HIV surveillance approaches according to Wilford Kirungi, a senior epidemiologist within the Ugandan Ministry of Health. This assertion was echoed by Joshua Musinguzi, former head of the AIDS control programme within the Ugandan Ministry of Health, who stated that SGS was developed:

To put together protocols that collect good biological data...biological markers...but at the same time behavioural data that can help us to explain the various trends...the dynamics of the trends that we were observing (Musinguzi: 27/01/2012).

Noting that older surveillance approaches to HIV/AIDS were limited in providing up-to-date surveillance data, Elizabeth Pisani, a former UNAIDS consultant, asserted the importance of getting decision-makers to understand the significance of conducting behavioural surveillance alongside serosurveillance:

We [UNAIDS] wanted to help people understand what a prevalence figure was giving them and we wanted people...to encourage people to think earlier in the epidemic. Because if you do behavioural surveillance well enough you can actually predict what might happen next (Pisani: 31/08/2011).

It was also claimed by Pisani that SGS was developed to create a degree of precision in relation to behavioural surveillance methodological approaches:

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<sup>6</sup> Triangulation can be defined as “a data analysis process in which multiple sources of data are considered together to come to a conclusion on a question related to an epidemic or intervention” (UNAIDS: 2013: pp. 61).

The behavioural part of second generation surveillance was to try and get some kind of rigour into behavioural surveillance...so that you would have data that were properly comparable...and because you had generalised epidemics...where everyone was thought to be at risk it seemed sensible to just integrate the behavioural surveillance (Pisani: 31/08/2011).

Highlighting the importance of integrating behavioural data sources, Manuel Carbello, the former chief of behavioural research within GPA, claimed that SGS was developed as older, serologically focused, HIV surveillance systems did not give decision-makers “any insights as to the socio-behavioural factors” (Carbello: 20/09/2011) that were contributing to ongoing patterns of HIV infection. Referring to the addition of behavioural data to serological data sources, Daniel Tarantola, a former senior employee of the GPA/former senior policy advisor to the Director General of the WHO, stated that SGS was developed to “bring colour to a black and white picture of the [HIV/AIDS] epidemic” (Tarantola: 27/10/2011). This particular phraseology can be interpreted as the colour being behavioural data which is added to complement the older black and white serological surveillance data.

Two individual themes relating to why SGS was developed also emerged from data analysis. The first distinct theme relates to the need for SGS to allow decision-makers to understand the structural causes, or sociological factors which influence patterns in HIV infection. The following data highlight the extent to which SGS expanded upon biomedically focused approaches to HIV surveillance. Frank Kaharuza, from CDC Uganda, claimed that SGS was developed to “de-medicalise” (Kaharuza: 13/02/2012) HIV surveillance approaches by allowing decision-makers to understand the precedent structural causes that influence the transmission of HIV:

I think it [SGS] increased the awareness of the precedent causes of HIV infection and acquisition...but even the broader aspect...to the whole social fabric...I think to me is what makes a difference. It [SGS] has de-medicalised HIV it's become a social thing...it's become a cultural thing...it's become everything. And people realise how each of these things have...kind of lead into managing HIV in this approach (Kaharuza: 13/02/2012).

The second individual theme, which is closely related to the theme of increasing the number and type of surveillance data sources, pertains to the SGS approach moving away from AIDS case reporting, which was the key methodological approach to quantifying AIDS mortality in the early stages of the global HIV/AIDS pandemic. Elizabeth Pisani, a former UNAIDS external consultant, advanced a detailed account relating to the development of SGS, which provides an historical insight into early HIV/AIDS surveillance methodological approaches and their respective limitations:

It [SGS] came about because HIV surveillance sort of started arse backwards right? Because...when we first started seeing AIDS cases...we didn't even know...what pathogen was...that caused that syndrome. So it started off with AIDS death reporting...which became mandatory very quickly...in a lot of countries. Once HIV was identified we realised...that by doing AIDS surveillance...you're actually tracking infections that happened maybe ten years ago. So it's telling you absolutely nothing about your evolving epidemic (Pisani: 31/08/2011).

The findings above suggest that SGS was introduced for a range of narrow reasons, which are broadly congruent with existing UNAIDS policy documentation. However, data indicate that SGS was also introduced for two broad reasons, which included the need for SGS to function as a marketing tool to promote the institutional identity of UNAIDS, and to bridge social scientific and epidemiological disciplinary approaches together in the mid-1990s. The notion of marketing was advanced by an HIV/AIDS official within the WHO. It was asserted that SGS was named in order to create an awareness of the new HIV surveillance approach itself and for SGS to function as a sound marketing tool for UNAIDS in the late-1990s and early 2000s. Indeed, it was claimed that the name SGS was not uninteresting and that SGS itself was constructed as a marketing breakthrough for UNAIDS.

These ideas about SGS performing the broader function to market improved HIV surveillance approaches for UNAIDS was echoed by Stefano Lazzari, former chair of the UNAIDS/WHO Working Group on Global HIV/AIDS/STI Surveillance, who framed the naming and development of

SGS as an effective rebranding exercise. Lazzari maintained that SGS helped the “re-launching of the whole idea of HIV surveillance in a more comprehensive way” (Lazzari: 21/09/2011) remarking that “the fact that it changed name” helped to “give it a new face” (Lazzari: 21/09/2011) which in turn facilitated “the reselling of the policy” (Lazzari: 21/09/2011). Lazzari also claimed that the naming of SGS was an effective policy rebrand that “wasn’t totally new...but the new packaging was attractive” (Lazzari: 21/09/2011).

Two additional interviewees noted that SGS functioned to market improved HIV surveillance approaches. Indeed, a former UNAIDS official claimed that the rebranding of SGS functioned to promote the institutional credibility of UNAIDS in the early 2000s:

So the policy rebrand or marketing in the early 2000s – I think it was in the early 2000s it was a marketing activity in the sense...that was the genius of Elizabeth Pisani to come up with this thing called HIV second generation surveillance. In fact, it’s not new because if you look – here in Geneva – there is second generation – I don’t know what...for some kind of huge multinational company. So it’s something that has come...and of course it [SGS] was a boost in authority for UNAIDS. UNAIDS picked up on this – the rebrand and of course then came the authority in [HIV/AIDS] surveillance (former UNAIDS official: 16/01/2013).

The notion that SGS functioned as a marketing, or rebranding tool, was posited by Frank Kaharuza, a former medical epidemiologist from CDC Uganda:

It is similar to what we have now in the sense that you have all these first generation, second generation computers, 3G’s...you’re looking at something that is an add on to what you have. So the critical question is what is it that is being added on? Like now we need to go a step further so what’s the sexy term...so second generation it’s a branding (Kaharuza: 13/02/2012).

Interview data also indicate that SGS served the broader function of unifying two formerly distinct disciplines (namely socio-behavioural disciplinary

approaches and epidemiological disciplinary approaches) within the newly formed institutional context of UNAIDS in 1996. This notion was advanced by Daniel Tarantola, a former senior employee of the GPA/former senior policy advisor to the Director General of the WHO. Tarantola claimed, when discussing the historical evolution of older HIV/AIDS surveillance methodologies, which had previously analysed epidemiological and socio-behavioural data sources in isolation, that:

In the mid-1990s, shortly after the launching of UNAIDS, there was a recognition that information gathering, or knowledge production if you will, had followed two tracks one was epidemiological and the other was social and behavioural through time limited research projects. So one was the social behavioural research area and the other was the epidemiological...so there was the need to bridge those two worlds both in terms of being able to focus strategies. So there was also a sort of disciplinary commitment to try and bridge those fields. So in the 1990s, when UNAIDS was launched, a lot of interest had already been generated around getting those two worlds together (Tarantola: 27/10/2011)

Tarantola also asserted that the process of integrating socio-behavioural and epidemiological approaches together was an easy process in the mid to late-1990s, as there was a commitment from HIV/AIDS experts to learn about the respective strengths of both disciplinary approaches. When discussing the process of disciplinary integration within UNAIDS, Tarantola claimed:

I think it was in a way easier at that time [mid-1990s] than it would be today. There is a lot of resentment today in the social science discipline about the response to HIV having become too medicalised...and so there is, I think today, a tension. But in those days it did not exist...there was actually a lot of enthusiasm on the part of public health workers to learn from social and political sciences and vice versa. I think that's what made this second generation surveillance guidelines and methods it merged the fact that people did want to work together and did want to cross the boundaries of disciplines (Tarantola: 27/10/2011)

However, a narrative contradicting the claims advanced by Daniel Tarantola was advanced by Stefano Lazzari, former chair of the UNAIDS/WHO Working Group on Global HIV/AIDS/STI Surveillance. In a discussion



about the reasons supporting the development of SGS, Lazzari commented upon the process of integrating socio-behavioural and epidemiological disciplinary approaches (and decision-makers from both disciplines alike) together:

Stefano Lazzari: I think it [SGS] required epidemiologists to work with behavioural scientists and this are different work [sic]...

*Interviewer: How easy was that?*

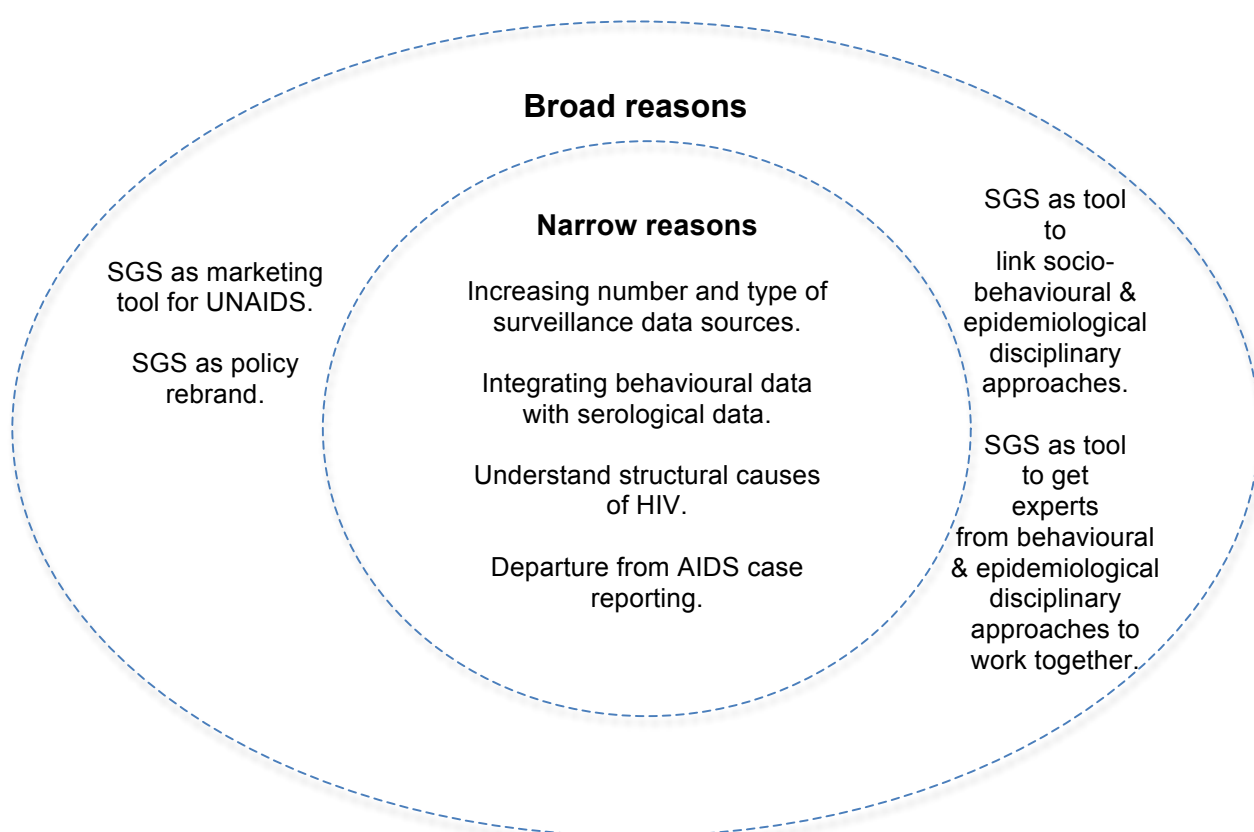
Stefano Lazzari: It wasn't easy at all. I think you had a whole generation of people who crossed over in a sense of behavioural scientists who started to understand statistics...real statistics and epidemiological data and vice versa epidemiologists who understood that you can live with uncertainties about things. But the basic concept behind second generation was also that you could triangulate data by multiple sources of information even if they weren't absolutely 100% accurate or even 80% accurate (Lazzari: 21/09/2011).

The process of integrating behavioural surveillance data, alongside existing serological surveillance data, and the process of merging socio-behavioural and epidemiological disciplinary approaches in the early-1990s, was advanced by an HIV/AIDS official within the WHO. It was maintained during interview that there was an institutional commitment to unify behavioural surveillance approaches with existing epidemiologically-based surveillance approaches. However, it was suggested that there was a degree of scientific conservatism, in relation to the integration of behavioural surveillance approaches in the early to mid-1990s, and that a degree of disciplinary resistance existed among epidemiologically focused HIV/AIDS experts. The notion of resistance to using behavioural surveillance data to build upon older, serologically focused HIV surveillance approaches, was described further by an HIV/AIDS official within the WHO—acknowledging that there were 'tribal' differences between socio-behavioural and epidemiological disciplinary experts in the early to mid-1990s.

The findings above indicate that SGS emerged for two broad reasons which included the need for SGS to function as a marketing tool to promote the institutional credibility of UNAIDS in the mid-1990s. Data also suggest that

SGS emerged to bridge two formerly distinct disciplines, namely socio-behavioural and epidemiological disciplines together (in order to enhance understandings of HIV/AIDS and to focus the direction of subsequent HIV prevention strategies advanced by UNAIDS). Findings appear to suggest that the process of bridging both disciplinary fields was viewed as an easy process by certain interviewees, whereas, others maintain that the process was more difficult—noting that there was a degree of scientific conservatism to integrate socio-behavioural (and qualitative-based data sources) to epidemiological and quantitative data sources in the early to mid-1990s. The following diagram provides a simple representation of the narrow and broad reasons that contributed towards the formal development of SGS by UNAIDS/WHO in the year 2000:

Figure 1 – Narrow and broad reasons that contributed towards the formal development of SGS



#### 4.6 Discussion – The genesis of a clearly defined problem and a contested evidence-base

Interview data above have demonstrated the central role of an HIV surveillance workshop held in Nairobi, Kenya between the 10<sup>th</sup> – 13<sup>th</sup> February 1997 in helping to develop the SGS approach and in gaining formative understandings of the Ugandan HIV prevalence decline of the 1990s. This particular UNAIDS sponsored event enabled attending HIV/AIDS experts to examine limitations with existing serologically focused HIV surveillance methodological approaches, and to analyse the sexual behavioural change reasons that could account for the Ugandan HIV prevalence decline of the mid-1990s. Importantly, the solution proposed at the workshop was to integrate behavioural data sources with existing serological surveillance data, which was intended to enable decision-makers to understand better evolving trends in HIV prevalence rates, their underlying behavioural determinants and the utility of behavioural data analysis in the development of subsequent HIV prevention policy. The workshop was therefore central in enabling the idea for SGS to ‘come about’ and in demonstrating the function of behavioural data in the creation of HIV prevention policy by global and national level actors. Importantly, the 33 attendees of the workshop, primarily through the presentation and critique of Ugandan and Zambian data were able to understand the potential value of building upon older, serologically focused HIV surveillance approaches with behavioural data sources—sources of information which could be used in the development of subsequent HIV prevention policy. These two country case study presentations at the workshop were therefore central in helping to justify the development of the SGS approach, the rationale for analysing behavioural data and its utility within the development of HIV prevention policy. Although other presentations from attending East African countries were given at the workshop, Ugandan data appear to have taken the lead role stemming from the well-established Ugandan HIV/AIDS surveillance system, the availability of behavioural data for analysis, and the formative signs of HIV decline emerging from the country in the early 1990s onwards.

It can be argued that the workshop was an example of a “focusing event” (Kingdon: 1995: pp. 94 – 95) where attending expert decision-makers were able to improve upon older HIV surveillance approaches through a working method which presented “centrepiece” (UNAIDS: 1998a: pp. 5) Ugandan behavioural surveillance data. Although focusing events are generally associated with crises such as aeroplane crashes, environmental accidents or natural disasters (Kingdon: 1995; Birkland: 1998) attention can also be turned to a specific problem if a “powerful symbol” (Kingdon: 1995: pp. 94 – 95) which “catches on” (Kingdon: 1995: pp. 94 – 95) amongst decision-makers is present for discussion. It could be argued that the “powerful symbol” (Kingdon: 1995: pp. 94 – 95) of Ugandan behavioural change data, and its association with the broader HIV prevalence decline emerging from the country, helped to focus attention with regard to improving older HIV surveillance approaches at the workshop with behavioural data sources. The problem of improving older HIV surveillance approaches at the workshop thus received “a little push to get the attention of people” (Kingdon: 1995: pp. 94 – 95) involved with improving older HIV surveillance approaches on the basis of Ugandan behavioural change data presented at the workshop.

Despite clear problem and solution identification at the workshop a range of competing narratives were advanced by interviewees relating to the actual evidence used to support SGS. It is important to state that the sources of evidence, which were used to help support the development of the SGS approach, appear to be both contested and complex. It is clear that multiple (and at times contradictory) narratives have been advanced relating to the evidence used to support the policy development of SGS. Although official UNAIDS documentation published after the workshop emphasises the important role of Ugandan and Zambian data, Elizabeth Pisani one of the co-authors of the UNAIDS documentation, downplayed the centrality of Ugandan behavioural data used to support the policy development of SGS during interview. Furthermore, the 300 small-scale sociological surveys, which are referred to as evidence demonstrating sexual behavioural change within Uganda, have been framed in a problematic manner by Elizabeth

Pisani as “mythical” and “mysterious” and by Michel Caraël as a source of “conflict” involving other decision-makers.

In addition to Pisani’s and Caraël’s narratives, it has also been demonstrated that other individual decision-makers had their own conceptualisations relating to the specific evidence used to support the development of the SGS approach. Reflecting on the various evidence narratives outlined above, it is clear that long-term GPA behavioural surveillance data, Ugandan behavioural data, behavioural survey data from high risk groups in New York and DHS data all appear to have informed the idea for SGS in a complex fashion. However, long-term GPA behavioural surveillance data, two Ugandan population-based surveys of sexual behavioural change conducted in 1989 and 1995 combined with 300 small-scale sociological surveys were officially cited as “centrepiece” (UNAIDS: 1998a: pp. 5) data used to enhance older HIV surveillance approaches by UNAIDS in the late-1990s.

Reflecting on the heterogeneous narratives described above, it can be suggested that the evidence used to support the idea for SGS built up gradually over time from a variety of geographical locales. However, the workshop was a central forum, or focusing event, which permitted the cadre of attending HIV/AIDS experts to showcase the value of Ugandan behavioural data to develop the idea for the SGS approach and to gain behavioural change understandings of the Ugandan HIV prevalence decline which, in turn, could influence the subsequent development of global HIV/AIDS prevention policy. In the process of examining the complex evidence-base used to support the SGS approach at the workshop, certain decision-makers, who were involved with the creation and analysis of behavioural data sources have been identified specifically: Michel Caraël, Daniel Low-Beer, Rand Stoneburner, Bernhard Schwartländer and Elizabeth Pisani. Importantly, these decision-makers, and their role in developing and interpreting behavioural evidence used to support SGS and global HIV prevention policy, will be critically investigated in greater analytical detail in the two subsequent results chapters. Greater attention will be given to these

individuals as it appears that Ugandan behavioural data, which were used to support the development of SGS and global HIV prevention policy, have been competitively analysed by these HIV/AIDS experts, which further complicate how evidence informed subsequent global HIV policy output produced by UNAIDS/WHO in the mid to late-1990s.

The findings above also indicate that SGS was introduced for a range of narrow and broad reasons. Echoing UNAIDS policy documentation, interview data suggest that SGS was introduced to improve older HIV surveillance approaches via the triangulation of multiple data sources. However, it was also ascertained that SGS was introduced for two broad reasons, namely, the need for SGS to function as a marketing tool to promote the institutional identity of UNAIDS, and to bridge social scientific and epidemiological disciplinary approaches (and decision-makers from both disciplines together) in the mid-1990s. The marketing of SGS has parallels with the notion of policy branding as in the case of Directly Observed Treatment – Short Course (DOTS) for tuberculosis control (Ogden et al : 2003: pp. 179). They noted that in the case of tuberculosis policy:

After a long period of neglect, resources were mobilised to put tuberculosis back on the international and national public policy agenda, and then how the policy was ‘branded’ and marketed as DOTS, and transferred to low and middle income countries (Ogden et al: 2003: pp. 179).

It could be argued that SGS was marketed for UNAIDS to generate attention towards this improved global HIV surveillance policy, and to boost UNAIDS’ institutional credibility in the mid-1990s, whilst helping to put HIV surveillance back on the public health agenda at the national and global levels. It was also discovered that SGS was introduced for a second broad reason, namely the function of SGS to unify two formerly distinct disciplinary approaches (and decision-makers from different disciplines). However, the claim that socio-behavioural and epidemiological decision-makers were successfully joined together via SGS is contested as two competing findings were advanced—with one stating that the process of integration was easy and another stating the process was difficult. This

broad-based function of SGS remains analytically unclear and thus requires further analytical examination in subsequent chapters.

#### 4.7 Chapter summary

This chapter has demonstrated that SGS emerged at a UNAIDS sponsored HIV surveillance improvement workshop held in Nairobi, Kenya in 1997. The findings presented, in relation to the development of SGS, are broadly congruent with UNAIDS policy literature, as the majority of interviewees highlighted the significance of the workshop in facilitating the idea for SGS to emerge at this specific forum—which can be viewed as a focusing event as advanced by Kingdon (1995). However, it is interesting to note that Michel Caraël the chair of the workshop (and the former head of HIV prevention within UNAIDS) claimed that the workshop should not be overemphasised, as attendees were purportedly convinced about the need to improve older HIV surveillance approaches prior to the workshop taking place. This narrative is intriguing as it appears to contradict official accounts that explain the policy development of SGS as advanced by UNAIDS in 1998.

While there was broad consensus about the historical development of SGS, the findings suggest that the sources of evidence used to support its introduction are both complex and contested. A range of competing narratives, pertaining to the evidence supporting the development of SGS, were advanced by the interviewees during data collection. Indeed, multiple, and at times, contradictory accounts about the evidence used to support the introduction of SGS were advanced by interviewees—which again call into question formal accounts relating to the evidence used to support the development of SGS as advanced by UNAIDS in 1998.

This chapter introduced the idea that the Ugandan evidence, used to support the introduction of SGS, namely 300 small-scale sociological studies, and two population-based surveys of sexual behavioural change conducted in the 1989 and 1995, are contested as experts involved with the analysis of these

data sources debated the sexual behavioural change reasons that were driving Uganda's HIV decline of the early to mid-1990s. Importantly, the narrative surrounding the contested nature of the Ugandan evidence requires further analytical exploration, and there is an analytical imperative to explore relevant factors that have shaped the evidence/policy dynamic relating to SGS in greater detail. Such exploration is warranted as the claims of a "catfight" (Pisani: 31/08/2011) and "misadventures" (Stoneburner: 05/08/2011) over Ugandan sexual behavioural change evidence may have affected how evidence, supporting the introduction of SGS, was used within policymaking networks at both the Genevan and Ugandan levels.

Findings also indicate that SGS was formally introduced by UNAIDS/WHO in the year 2000 for a range of narrow and broad reasons. In line within UNAIDS (1998a), SGS was introduced to improve older HIV surveillance methodologies via the integration, and triangulation of, multiple data sources. However, data also indicate that SGS also served two broader purposes—namely the need for SGS to function as a marketing tool to help promote the institutional identity of UNAIDS, and its role in attempting to integrate two formerly distinct disciplinary approaches (and decision-makers from different disciplines together). In summary, this chapter can state that the evidence supporting the development of SGS, and the reasons that led to its formal introduction in the year 2000, are much more complex than UNAIDS depicts within existing policy documentation. Significantly, the findings surrounding the contested nature of the Ugandan behavioural evidence, which helped justify the SGS approach at the workshop, require greater analytical examination as the underlying nature of the "misadventures" (Stoneburner: 05/08/2011) surrounding the Ugandan data sources remain analytically ambiguous.



## **CHAPTER FIVE: Examining competing explanations for Uganda's HIV prevalence decline of the 1990s via the analysis of SGS**

### **5.1 Introduction to chapter**

The previous chapter demonstrated that Ugandan evidence supporting the introduction of SGS were contested. It was discovered that certain experts involved with the development of SGS were purportedly involved in a “catfight” (Pisani: 31/08/2011) over the sexual behavioural change reasons that were ostensibly determining Uganda's HIV decline of the early to mid-1990s, namely debates over condom use versus partnership reduction, and their association with declining HIV trends. Notions of “conflict” (Caraël: 20/09/2011) and “misadventures” (Stoneburner: 05/08/2011) were also introduced, in relation to the Ugandan evidence used to support the introduction of SGS, and formative understandings of Uganda's HIV decline. While the previous chapter introduced the finding the Ugandan evidence supporting the introduction of SGS were contested, it did not examine the debate over the Ugandan evidence amongst HIV/AIDS experts in substantive analytical detail. Nor did it examine how experts, who supported different sexual behavioural change explanations, that emerged from the analysis of Ugandan evidence, attempted to legitimise their accounts of the Ugandan HIV decline, whilst discrediting the explanations of others, in HIV/AIDS policymaking networks.

Therefore, this chapter aims to examine how HIV/AIDS experts advanced competing explanations for the Ugandan HIV prevalence decline of the 1990s, whilst identifying strategies used to legitimise, and discredit, competing explanations in policymaking networks at the national and global levels. The chapter thus seeks to examine the contested role of Ugandan evidence, used to support formative understandings of the Ugandan HIV

prevalence decline of the 1990s, and the development of SGS whilst elucidating the competitive nature of debates over evidence amongst HIV/AIDS experts. In relation to the thesis as a whole, it is the task of this chapter to examine competing sexual behavioural change explanations advanced for the Ugandan HIV prevalence decline via the analysis of SGS, whilst considering the implications of the competitive debate over Ugandan evidence upon the broader relationship between evidence and policy in HIV/AIDS policymaking networks. Via this exploration it will be possible to understand the role of evidence used to support the introduction SGS, the contestation over the Uganda HIV prevalence decline of the 1990s, and to introduce relevant factors that influence the relationship between evidence and policy in HIV/AIDS policymaking networks at the global level.

## 5.2 Examining two competing sexual behavioural change explanations contributing towards declining HIV trends in Uganda

Interview data suggest that HIV/AIDS experts involved with the analysis of Ugandan behavioural data advanced two competing explanations that could be used to explain decreasing HIV trends within the country. The first explanation focused on increased condom uptake within the Ugandan population, linking this with the external involvement of international organisations in contributing to this sexual behavioural change. The second explanation emphasised a reduction in multiple partnerships within the Ugandan population, linking this to an endogenous process of increased HIV awareness in the Ugandan population, and the influence of oral communication in contributing to a process that did not involve the external involvement of international organisations. The following section will outline how HIV/AIDS experts aligned themselves with the competing explanations of increased condom uptake or a reduction in multiple partnerships.

### *5.2.1 Examining the alignment of experts to competing sexual behavioural change explanations*

The alignment of HIV/AIDS experts, to either an increased condom use or a reduction in multiple partnership explanation, was discovered to be a contested issue. Michel Caraël, the former head of HIV prevention within UNAIDS, described the alignment of HIV/AIDS experts to competing behavioural change explanations that could explain Uganda's HIV seroprevalence decline of the early to mid-1990s:

...there is indeed a controversy for more than 15 years now about the Uganda data and the explanation for the drop in sexual behaviour. So I enter into a conflict with [Helen] Epstein, [Daniel] Halperin, Rand Stoneburner, [Daniel] Low-Beer...who had different interpretations on how to explain it. And they came with an explanation about oral communication being the major factor and that condom use was not...I would not come back to that it's 15 years back we cannot rewrite the history (Caraël: 20/09/2011).

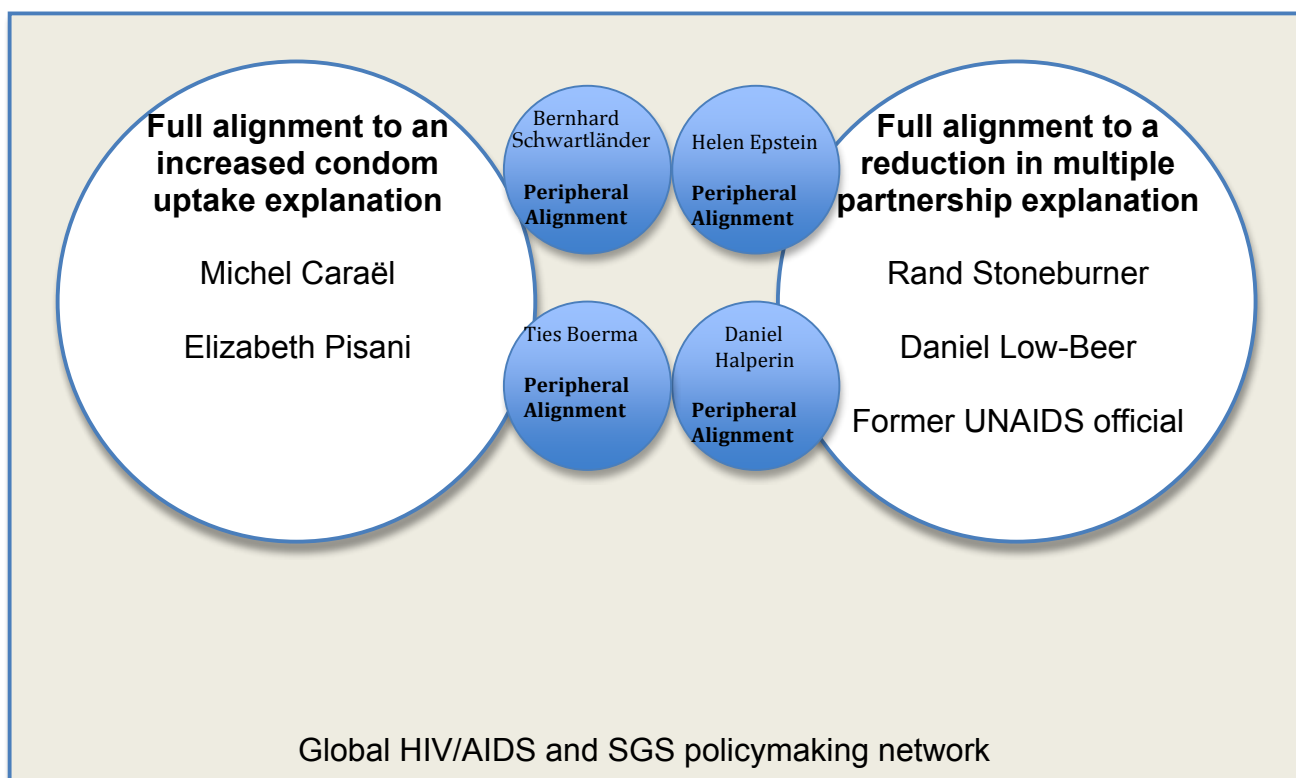
Caraël's account was reinforced by a former UNAIDS official who claimed that participants, involved with the analysis of Ugandan behavioural surveillance data, organised themselves into distinct groups according to their alignment to an increased condom uptake or a multiple partnership reduction explanation:

So you have one team looking at the [Ugandan] data one way with their own perspectives and views...and you have another team looking at it another way (former UNAIDS official: 16/01/2013).

The following diagram provides a simple representation of HIV/AIDS experts' alignment to the two competing explanations for Uganda's HIV seroprevalence decline based on a review of the interview material. 'Full-alignment' refers to participants who explicitly supported either increased condom uptake or a reduction in multiple partnership as the primary explanation for Uganda's HIV seroprevalence decline. 'Partial-alignment' refers to participants who did not fully align to either an increased condom

uptake or a reduction in multiple partnership explanation. Participants were roughly divided in relation to which explanation they favoured:

Figure 2 - Alignment to competing explanations for Uganda's HIV seroprevalence decline



Reflecting upon the figure above, it can be posited that Michel Caraël, the former head of HIV prevention within UNAIDS, and Elizabeth Pisani, a former UNAIDS consultant are fully-aligned to an explanation favouring increased condom uptake. Additional data, supporting the allocation of Pisani and Caraël to the fully-aligned grouping will now be examined.

### 5.2.2 Data sources supporting the full-alignment of experts to an increased condom uptake explanation

Supplementary evidence for Caraël's and Pisani's alignment with the condom explanation is drawn from UNAIDS policy documentation. A

UNAIDS report published after the 1997 Nairobi workshop, co-authored by Pisani and Caraël, claimed that Ugandan sexual behavioural surveys were demonstrating that younger age groups within urban areas were “delaying sexual activity and using more condoms than in the past” (UNAIDS: 1998a: pp. 3). This UNAIDS document also claims that:

With evidence compiled from more than 300 small-scale sociological studies, the survey results strongly suggest a rise in age of first sex and more condom use in cities (UNAIDS: 1998a: pp. 3).

Furthermore, within ‘A Measure of Success in Uganda – The Value of Monitoring both HIV Prevalence and Sexual Behaviour (UNAIDS: 1998b) increased condom uptake amongst the Ugandan population is claimed to be the primary behavioural change that occurred in Uganda between 1989 and 1995:

Between 1989 and 1995, the percentage of sexually active people claiming to use condoms increased significantly. For men, the proportion of people who said that they had ever used a condom rose from 15% to 55% and for women from 6% to 39% (UNAIDS: 1998b: pp. 10).

Reflecting upon “evidence compiled from more than 300 smaller-scale sociological studies” (UNAIDS: 1998a: pp. 5) that were reviewed by anthropologist Tom Barton, UNAIDS also claimed that:

Many studies indicate an increase in condom use, and some of these have followed the same cohorts over time. Taken together, these would suggest that the proportion of sexually active people who had ever used a condom at the national level rose between 1987 and 1996 from about 3% to 25% (UNAIDS: 1998b: pp.10).

UNAIDS policy documentation (UNAIDS: 1998a; 1998b) thus emphasised increased condom uptake at *the* salient factor emerging from an analysis of multiple Ugandan data sources. The condom-based explanation is also found in an academic paper written by Asimwe-Okiror et al (1997) that was published in the journal AIDS in 1997 (please note that Michel Caraël

contributed towards the development of this journal). Asiimwe-Okiror et al (1997) assert that:

During the study period, a 2-year delay in the onset of sexual intercourse among youths aged 15-24 years and a 9% decrease in casual sex in the past year in male youths aged 15-24 years were reported. Men and women reported a 40% and 30% increase in the experience of condom use, respectively. In the same study area, over the same period, there was an overall 40% decline in the rates of HIV seroprevalence among pregnant women attending antenatal clinics. *It can be hypothesized that the observed declining trends in HIV correspond to a change in sexual behaviour and condom use, especially among youths* [italics added] (Asiimwe-Okiror: 1997: pp. 1157).

Thus, these authors highlighted increased condom use as *the* most significant sexual behavioural change which could explain declining trends in HIV seroprevalence among pregnant women who attended ANCs within urban areas of Uganda. Significantly, the study concluded that the sexual behavioural change findings “should encourage AIDS control programmes to pursue their prevention activities” (Asiimwe-Okiror: 1997: pp. 1157) which included the promotion of condoms.

### *5.2.3 Data sources supporting the full-alignment of experts to a reduction in multiple partnerships uptake explanation*

As indicated in Figure 1, Rand Stoneburner, Daniel Low-Beer and a former UNAIDS official supported a reduction in multiple partnerships as *the* primary explanation contributing to Uganda’s HIV seroprevalence decline—a behaviour change arising from growing awareness in the Ugandan population about the risks of HIV/AIDS. Rand Stoneburner, a former GPA/UNAIDS epidemiologist, described the awareness of HIV/AIDS amongst the Ugandan population when reflecting upon his time spent in the country in the early to mid-1990s:

In Uganda...I noticed, talking to cab drivers and other people, that in Uganda you’d ask them about AIDS and you couldn’t get them to stop talking about all the people in their family that died

and what's going on in their communities. You'd go to Malawi and they'd be embarrassed...so complete denial. But in Uganda, it was just completely open and they had an opinion about what to do, and what the church was doing, and whether the Pope was right in saying to not use condoms. But at least they were debating it and it was palpable. It was amazing and we tried to look for empirical evidence of that (Stoneburner: 05/08/2011).

However, this explanation failed to gain traction within global HIV/AIDS policymaking networks from the mid to late-1990s onwards. Stoneburner, a former GPA/UNAIDS epidemiologist, claimed that the reduction in multiple partnerships explanation was not published until 2004 as his explanation, contradicted the increased condom uptake explanation as advanced by UNAIDS (1998a; 1998b) and Asiimwe-Okiror (1997). He also asserted that funding was required from USAID to publish the reduction in multiple partnerships explanation having left UNAIDS in the mid-1990s. The data below highlight Stoneburner's view of his role in analysing Ugandan data, and the extent to which he was marginalised within UNAIDS:

I was kind of the last one when everybody else in GPA was finding other jobs...I was so involved in the Ugandan data I was just immersed in it because it was fascinating and I didn't continue with UNAIDS. I was *persona non grata* over all this Uganda...and USAID gave me some funds (Stoneburner: 05/08/2011).

Stoneburner felt that Michel Caraël's condom explanation received institutional support from UNAIDS, whereas Stoneburner was obliged to obtain ad hoc financial support from USAID to publish his multiple partnership reduction explanation (Stoneburner & Low-Beer (2004) Population-Level HIV Decline and Behavioural Risk Avoidance in Uganda, Science, Vol. 304, No. 5671, pp. 714 – 718):

Michel's [Caraël's] data, he had institutional support to continue to do that through UNAIDS. I had institutional support sort of piecemeal from USAID to continue to investigate this, with the triangulation that eventually came out in Science [in 2004] (Stoneburner: 05/08/2011).

Stoneburner emphasised the difficulties he faced in publishing his account of the Ugandan HIV decline. He noted that another analysis of data – emphasising the role of increased condom uptake – was published some time before his own paper in *Science* and that this undermined the dissemination and credibility of his analysis (highlighting a reduction in multiple partnerships):

We tried to publish a paper with the Ugandans about this [the Ugandan HIV decline]. They were really keen on it and UNAIDS was publishing a parallel paper. I was responsible for the epidemiology and there was another guy from UNAIDS [Michel Caraël] who was basically doing the social science part of the survey and their paper came out first [Asiimwe-Okiror et al: 1997]...and I said ah shoot! Well, you know, at least it's out there...and this was fine, at least it's out there. And I read through it, I said this isn't...these aren't our findings. It basically said there was a modest change in sexual partners (Stoneburner: 05/08/2011).

Thus, the increased condom uptake explanation appears to have been widely disseminated as *the* principal reason for Uganda's HIV decline in the mid to late-1990s sometime before the reduction in multiple partnerships explanation appeared in the public domain in 2004. The above data illustrates that some interviewees – particularly Rand Stoneburner – felt Ugandan data had been misinterpreted by UNAIDS/WHO experts in the late 1990s with Michel Caraël playing a key role in this. The personalised and somewhat provocative nature of some of the claims presented highlight the extent to which such discussions were seen as both contentious and significant in terms of professional standing and credibility.

Two contextual factors that may have contributed to the somewhat fraught nature of these discussions include the political significance of Uganda's HIV decline in the 1990s and the absence of a conclusive evidence-base that could definitively support *either* an increased condom uptake explanation *or* a reduction in multiple partnership explanation as the key factor behind Uganda's HIV prevalence decline. Professor Thomas Rehle, a UNAIDS/WHO consultant who helped develop SGS in the late-1990s, asserted that the need to portray the narrative of Ugandan HIV 'success'



influenced the interpretation of sexual behavioural change data by HIV/AIDS experts from global-level institutions:

In Uganda a lot of people wanted to portray a success story. So it was very much needed to have a success story and there were people included around the Global AIDS Programme and the WHO and so on. So there was this need to have a success story and to have explanations and make sure that things worked and then they attributed all kinds of findings to things they had done in the field. Of course, this was not always really evidence-based. So there was a lot of interpretation issues here and counterfactual interpretations were always possible (Rehle: 23/11/2016).

Professor Thomas Rehle, a UNAIDS/WHO consultant involved in the development of SGS, notes that there was a dearth of Ugandan behavioural evidence which could not allow HIV/AIDS experts in the mid-1990s to support *either* a condom uptake explanation *or* a reduction in multiple partnership explanation. Professor Rehle claimed that HIV/AIDS experts in the 1990s relied on anecdote rather than evidence in relation to supporting competing behavioural explanations for the Ugandan HIV decline:

Was it the condom use...reduction in partners? Well it depends what partnerships, what types of risk behaviours they have in these diets...so all these really nitty-gritty pieces were not there to really make a case for this one or the other explanation. People had to resort on anecdotal stuff or some little focus groups and so on – but most of this stuff was not even published. So there is a reason for researchers and for scientists...there was a lot of food for contention – there is no doubt (Rehle: 23/11/2016).

Professor Thomas Rehle also contextualised the lack of consensus relating to the contested interpretation of Ugandan sexual behavioural data and the broader political context that surrounded the process of data interpretation by competing HIV/AIDS experts:

There were definitely different opinions, different interpretations and people were then...the more they were digging into...the more they defended their position and there was not a real consensus. Like I said, to make really informed decisions on the data, or to make a decision...yes this was multiple partnerships versus condom use you would have needed very more insightful data in a qualitative context. Like I said, this was a political environment to make such claims and you were

successful...embraced by people who were funding this whole thing...many public health findings will be often used in the context for some people to provide the most beneficial outcome (Rehle: 23/11/2016).

On a broader level, Professor Thomas Rehle also posited that despite the absence of a comprehensive evidence-base (to support either an increased condom uptake explanation or a reduction in multiple partnership explanation) there was a wider public health need to make definitive statements based on anecdote – particularly during the mid-1990s – when HIV / AIDS was a growing global public health problem:

Well this is a typical public health situation – you don't have enough data but you have to give some explanations for many constituencies and stakeholders. As a researcher...there was not enough evidence and data to make these strong statements. But it was necessary, at this time, to make these statements because the overriding...the overall good was that we get more funding for these overall [HIV / AIDS] projects (Rehle: 23/11/2016).

Given the apparent ambiguity over the reason for Uganda's HIV decline in the early 1990s, it is helpful to consider why an increased condom uptake explanation came to dominate global HIV policy discourse at that time. The following three sections will examine strategies used by experts in the UNAIDS/WHO community to advocate for particular explanations within global HIV / AIDS policymaking networks. Such examination will enable this chapter to examine the competitive nature surrounding the analysis of Ugandan evidence, used to support the development of SGS, and formative behavioural change explanations for the Ugandan HIV decline. The following three sections will outline claims of disciplinary bias amongst competing experts involved with the analysis of Ugandan data sources, the role of policy entrepreneurship as a strategy to legitimise an increased condom uptake explanation, and claims of Ugandan sexual behavioural change data misinterpretation (and its purported influence upon the reduction in multiple partnerships explanation).

### 5.3 Claims of disciplinary bias and its influence upon competing behavioural change explanations

Several participants appeared to question each others' claims regarding the interpretation of Ugandan data sources on the basis of contrasting disciplinary backgrounds. Explanations of multiple partnership reduction, primarily advanced by experts with an epidemiological or biomedical background, were framed as methodologically inadequate by other experts who possessed a social-scientific or socio-behavioural disciplinary background—including Michel Caraël, the former head of HIV prevention within UNAIDS. Caraël suggested that Rand Stoneburner's explanation, which focused on a reduction in multiple partnerships, was a limited one stemming from Stoneburner's epidemiological background:

So when Stoneburner and others come in with their data, their interpretations of social behavioural data that they have no clue about...Rand Stoneburner is a hardcore epidemiologist and I'm not sure that he understands himself what he's doing with modelling data and corrections and things like this (Caraël: 20/09/2011).

Caraël also suggested that underlying disciplinary bias resulted in Stoneburner interpreting data on sexual behavioural change in a biomedically oriented manner that failed to incorporate the social dimensions of behavioural data itself:

...social institutions, perceptions, institutes...you know ideology things like that...I mean its completely lacking for epidemiologists because it's not part of their...on their radar screen; they take data as data (Caraël: 20/09/2011).

The construction of Stoneburner as an epidemiologist and Caraël as a social scientist, was emphasised by Rand Stoneburner: "yeah they [other UNAIDS decision-makers] were saying...you know this guy isn't a behavioural scientist the real behavioural scientist was Michel [Caraël]" (Stoneburner: 24/03/2013). This was also emphasised by a former UNAIDS official: "you had Michel Caraël who's more a social scientist and on the other hand you

have Rand Stoneburner who is really the pure epidemiologist” (former UNAIDS official: 16/01/2013).

### *5.3.1 Claims of disciplinary bias as a strategic framing technique*

The explanation for Uganda’s HIV decline, based on increased condom use, appears to have gained wider acceptability within HIV/AIDS policymaking networks than the competing explanation focused on a reduction in multiple partnerships. Caraël’s statements suggest he links the dominance of his favoured explanation (increased condom use) with his status as an expert social scientist who could interpret socio-behavioural data more competently than Stoneburner. In contrast, he frames Stoneburner as a pure epidemiologist whose underlying biomedical background made him ill-equipped to interpret data on changes in sexual behaviour. Interview data suggest that the participants’ disciplinary background were used to claim expertise, or inadequacy, in relation to their different interpretations of Ugandan behavioural data. The construction of certain HIV/AIDS experts as being unable to analyse Ugandan sexual behavioural change data, stemming from their underlying disciplinary background, may have influenced the perceived credibility of a multiple partnership reduction explanation for declining HIV trends in Uganda since the early 1990s.

The idea that a social scientific interpretation of Ugandan data should dominate a more epidemiologically-informed explanation seems to counter the tendency for biomedical data, and methods, to control discussions about evidence in health policy. Indeed, during the period relating to these discussion, the biomedical paradigm was seen as dominating HIV/AIDS discourse (Tarantola: 2000: pp. 1). The claim of expertise, advanced by Caraël, is therefore of particular interest, and may have represented a deliberate strategy for advancing the credibility of his preferred explanation. Caraël’s claims about Stoneburner’s disciplinary bias were possibly used as a discrediting strategy to give greater credence to Caraël’s favoured explanation (i.e. increased condom uptake) for Uganda’s HIV decline. Having examined claims of disciplinary bias and the possibility that these

claims were advanced by competing participants for strategic reasons, it is necessary to examine a second strategy which appears to have facilitated an increased condom uptake explanation to dominate a reduction in multiple partnership explanation—namely policy entrepreneurship.

#### 5.4 Policy entrepreneurship as a strategy to facilitate an increased condom uptake explanation

Kingdon (1995) maintains that it is possible when researching policy case studies to “pinpoint a particular person or at most a few persons, who were central in moving a subject up on the agenda and into position for enactment” (Kingdon: 1995: pp. 180). This section of the chapter will support this contention by presenting interview data to illustrate that Michel Caraël, the former head of HIV prevention within UNAIDS, functioned as a policy entrepreneur within global HIV/AIDS policy networks, advocating for the increased condom uptake explanation as the main cause of Uganda’s HIV decline in the early to mid-1990s.

Prior to examining this strategy, it is necessary to define what policy entrepreneurs are, how they operate within policy networks, and what motivates them to take an active role within the policymaking process. According to Kingdon (1995), policy entrepreneurs are individuals who possess three central qualities. First, policy entrepreneurs possess a known level of expertise which in turn gives them a legitimate claim to hearing within a policy network. Second, policy entrepreneurs are known for their negotiating skills and their political connections. Third, policy entrepreneurs are persistent and tenacious individuals who aim to push their ideas about policy problems and how to address them in multiple fora (Kingdon: 1995: pp. 180 – 181). According to Kingdon (1995) the primary incentive which motivate policy entrepreneurs to function within the policymaking process is the promotion of personal interest—this may include protecting one’s bureaucratic turf, maintaining one’s employment, expanding one’s agency and personal career promotion (Kingdon: 1995: pp. 123).

Interview data suggest that Michel Caraël possessed a legitimate claim to hearing within global HIV/AIDS policymaking networks underpinned by his perceived expertise as a socio-behavioural scientist. Indeed, Caraël was defined as a “key mover” in relation to behavioural surveillance methodological approaches within sub-Saharan Africa—this notion was raised by Manuel Carbello, the former chief of behavioural research with the GPA (Carbello: 20/09/2011). Caraël was also noted as being directly involved with the critical appraisal of Ugandan behavioural data—in relation to HIV/AIDS surveillance policy “particularly in sub-Saharan Africa there were gentlemen like Michel Caraël involved with the process”—Alex Opio, assistant commissioner for national disease control within the Ugandan Ministry of Health (Opio: 14//02/2012). Joshua Musinguzi, former head of the AIDS control programme within the Ugandan Ministry of Health, emphasised the central role of Michel Caraël in relation to conducting Ugandan sexual behavioural studies “Michel Caraël was especially instrumental in the behavioural studies we were doing here” (Musinguzi: 27/01/2012).

In relation to the development of SGS, which used Ugandan sexual behavioural studies to support its introduction, Daniel Tarantola, a former senior employee of the GPA/former senior policy advisor to the Director General of the WHO also commented on the central role of Michel Caraël. Tarantola remarked during interview that despite a “whole group” (Tarantola: 27/10/2011) of people being involved with the policy development of SGS, Michel Caraël was “one of the most engaged” individuals involved with its development (Tarantola: 27/10/2011). Commenting on his own role in relation to the policy development of SGS, Michel Caraël stated “I don’t want to personalise it because it would be unfair - but for sure I consider myself as key in UNAIDS” (Caraël: 20/09/2011).

It was also claimed by a former UNAIDS official that Michel Caraël, stemming from his socio-behavioural expertise, possessed a close and productive working relationship with Peter Piot, the former Executive

Director of UNAIDS. Indeed, he was framed as a “guru” of socio-behavioural data analysis by Peter Piot according to a former UNAIDS official “Michel Caraël was the guru of this thinking and was the one who Peter Piot kept on-board” (former UNAIDS official: 19/9/2011). This notion was reiterated by the former UNAIDS official:

Michel Caraël was the guru of Peter Piot and his voice was heard and he didn't listen to the others. And so at the end of course it was the data and the truth from Michel Caraël that came across...his thinking was what went into the UNAIDS secretariat (former UNAIDS official: 19/9/2011).

This relationship with Peter Piot, the former Executive Director of UNAIDS, could be viewed as illustrating a facet of policy entrepreneurship as advanced by Kingdon (1995) namely their political connections and negotiating skills. It could be argued that Caraël's productive relationship with Peter Piot, the most institutionally senior decision-maker within UNAIDS, could have facilitated Caraël's ability to negotiate his explanation of Ugandan sexual behavioural change to gain wider political acceptance within UNAIDS than other competing sexual behavioural change explanations.

On the basis of the interview data presented above, Michel Caraël could be viewed as a central actor within the policymaking domain of global HIV/AIDS surveillance. It could be argued that Michel Caraël was able to take a central role within the network of decision-makers involved with global HIV/AIDS surveillance stemming from the actual size of the SGS policy network itself. Importantly, the SGS policy network was relatively compact, perhaps stemming from the esoteric nature of global HIV/AIDS surveillance, and the limited stock of experts involved within this policy field at the global level. The compact size of the SGS policy network was described by an HIV/AIDS official within the WHO, claiming that it is possible to count to number of HIV/AIDS experts, involved with global HIV/AIDS surveillance on the fingers of two or three hands. The notion that

global HIV / AIDS surveillance policy networks were quite compact was also emphasised by Elizabeth Pisani, a former UNAIDS external consultant:

...and here's what we a bunch of twenty people in the world not even that many fifteen people in the world...whatever it was decided after a review of the existing data (Pisani: 31/08/2011).

It could be argued, stemming from the small size of global HIV / AIDS policy networks, that Michel Caraël was able to function as a policy entrepreneur which facilitated his own ideas about Ugandan sexual behavioural change to permeate through global HIV / AIDS policy networks ahead of other competing explanations. By possessing a legitimate claim to hearing, and the appropriate socio-behavioural expertise within the global HIV / AIDS policy networks, it can be tentatively reasoned that Michel Caraël may have actively functioned in an entrepreneurial fashion as a strategy to legitimise his increased condom uptake explanation. It can also be argued that Caraël's close relationship with Peter Piot, the former Executive Director of UNAIDS, was a useful political connection to possess—arguably such a political connection may have been utilised by Caraël to promote his analysis of Ugandan sexual behavioural change data more effectively than other competing HIV / AIDS experts.

### 5.5 Claims of Ugandan sexual behavioural change data misinterpretation

This section of the chapter presents claims of Ugandan sexual behavioural change data interpretation and possible misinterpretation. A small number of interviewees suggested there may have been a degree of misinterpretation in the analysis of Ugandan data which was seen as contributing to the dominance of explanations emphasising an increase in condom use as the main explanation for Uganda's HIV decline.

Prior to examining the claims of Ugandan data misinterpretation, it is also important to state that the interview data outlined below are understood by the author as an artefact of the contentious “catfight” (Pisani: 31/08/2011) that apparently took place between competing participants who attempted to



explain Uganda's HIV seroprevalence decline of the early to mid-1990s. The material presented is intended to reflect the range of perspectives presented during interviews, some of which involve fairly personalised claims. The following parts of the chapter are organised into two sub-sections. The first sub-section will present the claim of Ugandan sexual behavioural change data misinterpretation, the specific Ugandan data sources which were potentially influenced by the alleged process of data misinterpretation, and the key participants involved with the purported process of Ugandan data misinterpretation itself. The second sub-section will examine the relationship between the claim of Ugandan data misinterpretation, its associated relationship with the emergence of SGS and the development of explanations for the Ugandan HIV prevalence decline of the 1990s.

#### *5.5.1 Examining the claim of Ugandan sexual behavioural change data misinterpretation*

A small number of interviewees suggested there may have been a degree of data misinterpretation in relation to Ugandan sexual behavioural change evidence and the contrasting explanations advanced for Uganda's HIV decline, specifically, these claims relate to the purported oversight of a 60% reduction in multiple partnership finding that emerged from an analysis of two Ugandan population-based surveys of sexual behavioural change conducted in 1989 and 1995. Stoneburner suggested that this reduction in multiple partnerships was overlooked by some experts, thus increasing the apparent significance of increased condom use as highlighted in Asiimwe-Okiror et al (1997) and 'A Measure of Success in Uganda' (UNAIDS: 1998b). This purported misinterpretation was seen as seemingly "confound[ing] the understanding of HIV dynamics in Uganda" (Stoneburner & Low-Beer: 2004: pp. 714) since Stoneburner & Low-Beer saw the 60% reduction in multiple partnership as "an important and perhaps overlooked measure of behaviour change" (Stoneburner & Low-Beer: 2004: pp. 715) that took place within Uganda between 1989 and 1995. This is reiterated – and stated even more strongly – in the following quotes from Stoneburner:

The amazing thing is that they [UNAIDS] eliminated the 60 percent decline in multiple partners and you asked was this the condoms? Or the fact that we're having one partner? But they [UNAIDS] eliminated that key indicator (Stoneburner: 05/08/2011).

I think they [UNAIDS] were being fraudulent. They made it – they did something to make some, they obscured it [finding of multiple partnership reduction] which I think but they obscured it with the intent - a mal intent (Stoneburner: 05/08/2011).

Stoneburner notes that the authors of Asiimwe-Okiror et al (1997) referred to “only a 9% decline in casual sex among men and increases among women (Stoneburner & Low-Beer: 2004: pp. 716) and thus overlooked the significance of reduced sexual partnerships as an explanation for Uganda's HIV decline. Stoneburner regarded Michel Caraël, the former head of HIV prevention within UNAIDS, as the key person responsible for this interpretation:

We [Rand Stoneburner & Michel Caraël] were supposed to be writing up papers in tandem. I was doing it on the prevalence decline, the dynamics, and he [Michel Caraël] was doing all the social behavioural stuff and mine was sort of overlapping with his. And that's when I learned that he [Michel Caraël] had manipulated the data in a manner to make the partnership go away and that was in 1996 and 1997 (Stoneburner: 24/03/2011).

The purported misinterpretation of Ugandan behavioural data was also advanced by Rand Stoneburner & Daniel Low-Beer in their 2004 Science article, which posited their counter-explanation to the increased condom uptake explanation advanced by Michel Caraël and Elizabeth Pisani from 1996 onwards:

A comparative analysis of 1995 and 1989 Ugandan population-based surveys of HIV behavioral risk indicators offered evidence of important changes since 1989, including an increase in the age of sexual debut, a decrease in indicators of casual or nonregular partners, and an increase in the use of condoms, both overall and in casual partnerships. The subsequent report, led by the Joint United Nations Programme on HIV/AIDS (UNAIDS), emphasized the relative importance of sexual debut and condom use. *An important and perhaps overlooked measure of behavior change*

*in Uganda between 1989 and 1995 was a 60% reduction in persons reporting casual sexual partnerships in the past year, evident in urban and rural populations* [italics added] (Stoneburner & Low-Beer: 2004: pp. 715).

Stoneburner also claimed that when he attempted to advance his explanation of sexual behavioural change, that could be associated with declining HIV seroprevalence rates within Uganda, there was a degree of reluctance within UNAIDS to internalise this finding:

When we [Stoneburner & Low-Beer] came back with the data and kind of showed it at a meeting...the field people [working within Uganda] were really excited they said gosh something is really going on here something is working and it kind of got - the door got slammed shut on it. It was then very difficult to get it out (Stoneburner: 05/08/2011).

A narrative advanced by Stoneburner also highlights the contested nature of Ugandan behavioural data analysis, which echoes Elizabeth Pisani's "catfight" (Pisani: 31/08/2011) notion outlined above. The claim below again indicates that the process of Ugandan behavioural data analysis was highly contested and it also reiterates Stoneburner's claim of Ugandan data misinterpretation, which, again, should be understood as an artefact of the contested process of participants' attempts to distil Uganda's HIV seroprevalence decline into its constituent aspects:

I was then invited...kind of as an afterthought to this meeting [the 1997 Nairobi workshop] because I was already sort of on the warpath with UNAIDS and the cabal of Ties Boerma and Bernhard [Schwartländer] and Elizabeth Pisani...but all of this had sort of been evolved and denied by UNAIDS. So their second generation surveillance was not acknowledging too much on what was going on in Uganda because Michel Caraël had already, you know, re-written some of the data (Stoneburner: 24/03/2011).

One other interviewee suggested Ugandan data may have been misinterpreted by UNAIDS/WHO experts. A former UNAIDS official referred to 'fuzzed up' data and 'dirty politics':

Well the story between Michel Caraël and [Elizabeth] Pisani with [Bernhard] Schwartländer I know this story very well and that's why, for me, I moved away from that because I find this dirty politics. And I love all these people I work with them closely and Rand Stoneburner go and speak to his friend Daniel Low-Beer and Uganda they fuzzed up the data (former UNAIDS official 19/09/2011).

The interviewee went on to state "I never wanted to get into this - but they [unnamed UNAIDS decision-makers] played with the data" (former UNAIDS official: 19/09/2011), suggesting this had a significant impact on the interpretation of Uganda's HIV decline:

...the interpretation on the condom use and sexual partners and the statistics behind were if not falsified they were not reported correctly (former UNAIDS official: 19/09/2011).

Some Ugandan participants, one of whom was involved with the Asiimwe-Okiror et al (1997) publication, also appeared to be sensitive to the notion that different participants from UNAIDS were analysing Ugandan sexual behavioural change data in a heterogeneous manner. Indeed, Joshua Musinguzi, former head of the AIDS control programme within the Ugandan Ministry of Health, who collaborated on the Asiimwe-Okiror et al (1997) publication with Michel Caraël, commented upon different data interpretations advanced by competing participants:

When we [Ugandan Ministry of health officials] did collect our information we actually worked in collaboration...I remember we did have lots of discussions, internally first, and also with the group from there...Rand [Stoneburner] and Daniel Low-Beer and I think Michel Caraël and others to look at the processes...now the interpretation and the analysis and the usage I know that people were interpreting data variously (Musinguzi: 27/01/2012).

Comments relating to the process of Ugandan behavioural data interpretation, that occurred during the institutional transition from GPA to UNAIDS between 1995 and 1996, were also advanced by Musinguzi:

What I know is...I think what was difficult for them [competing participants] was when they were transitioning to GPA to

UNAIDS and I think there were some feelings with some of them...there were issues. There were them [sic] who did not move over from one to the other...what I know is there continued to be some turbulence within themselves. I don't know to what extent that was probably an issue with the usage of data. What I was always sure about was the quality of the data. But how they used it and how people interpreted it was always different (Musinguzi: 27/01/2012).

Musinguzi also indicated that issues arose when individual HIV/AIDS experts started to interpret the Ugandan sexual behavioural data itself:

For us [the Ugandan Ministry of Health] what we always insisted on was to ensure that the data we collect are of the highest quality. But I think there was a price at some stage and people may have worked for it in different ways (Musinguzi: 27/01/2012).

#### *5.5.2 Ugandan sexual behavioural change data misinterpretation and its relationship with the development of SGS*

Interview data were also generated by participants from Uganda who assert that the contested Ugandan sexual behavioural change data, which were used to support the development of SGS, and to provide explanations of Uganda's HIV seroprevalence decline, were competitively interpreted by participants. The narrative below provided by Professor David Serwadda, director of the institute of public health at Makerere University, advances the key notion that participants attempted to "slice and dice" (Serwadda: 06/02/2012) the sexual behavioural change reasons contributing to Uganda's HIV seroprevalence decline which in turn "messed" (Serwadda: 06/02/2012) the formative interpretations of Uganda's HIV seroprevalence decline:

This is basically the crux of the matter. Now if you're going to talk about politics in second generation surveillance it was driven truly by understanding the dynamics of the epidemic. So when we started to collect behavioural indicators then, you know, people wanted to slice it into whether it's reduction of sexual partner, whether it's condom use, whether it was abstinence that was really driving this. And that's where really...issues of real politics at the local stage really started to come in...depending on who you talk to and who was a strong

advocate of what. That really sort of messed us up a bit (Serwadda: 06/02/2012).

Serwadda's narrative below relates to the attempts of various actors involved with global HIV/AIDS policy to understand which specific behavioural factors were contributing to Uganda's HIV prevalence decline, and the manner in which individuals were using Ugandan behavioural evidence to advance their own sexual behavioural change preferences:

So to go back to second generation...we were seeing these [sexual behavioural] changes but we needed to get handle onto it but the [sexual behavioural] changes were going into the right directions for politicians on one side for donors on the other. Everybody wanted to have a bite on this success [the Ugandan HIV seroprevalence decline]. And therefore, it was basically trying to get the evidence that would justify what they believed. So that is the politics of it. I think the original intention was...I don't think in my opinion a very political thing it was very logical. But what happened was that you know? When they started to slice and dice the behaviour change and what might be contributing more that's when we got in very muddled water (Serwadda: 06/02/2012).

Rand Stoneburner, a former GPA/UNAIDS epidemiologist, also claimed that Ugandan sexual behavioural change data, which were used to support the development of SGS, and to understand the sexual behavioural change reasons contributing to Uganda's emerging HIV decline, were interpreted and presented in a political manner by other UNAIDS decision-makers:

I think the idea of moving into second generation surveillance was a very important progression in our ability to better monitor the epidemiological and social dynamics of the epidemic. I think the shortcoming was the way in which the data was [sic] interpreted and presented in very politically self-serving manners (Stoneburner: 24/03/2013).

The notion that distinct "teams" (former UNAIDS official: 16/01/2013) of decision-makers, who were involved with the formative analysis of Ugandan sexual behavioural change data sources, and the notion that Ugandan statistics were possibly misinterpreted, was raised by a former UNAIDS official. The narrative below outlines this participants' understanding of the

purported process of Ugandan data misinterpretation and the manner in which data were “played” (former UNAIDS official: 16/01/2013) with to determine what was statistically significant or not in relation to Ugandan sexual behavioural change:

So you have one team looking at the data one way with their own perspective and views...and you have another team looking at it another way. My thinking is you can interpret and analyse data and come up with maybe quite some different stand [sic] than another team if you start to play with statistics. And like you maybe look at some variables and forget the others...you can look at some data...forget some other sources...you can look at some ranges and play with the ranges and say this is statistically significant or not. And this is exactly what happened I think in Uganda...that’s how you interpret differences between the people (former UNAIDS official: 16/01/2013).

It is important to state that this former UNAIDS official attempted to function as a neutral arbiter during interview (attempting to provide a balanced account of the contested process of Ugandan sexual behavioural change data analysis) and the manner in which competing HIV/AIDS experts took part with the purported process of data misinterpretation. However, towards the end of the first interview the participant acknowledged that an increased condom uptake explanation was ostensibly presented as *the* salient behavioural change explanation that was contributing to Uganda’s HIV seroprevalence decline:

So something happened around then [1996 – 1997] and that is where you can’t deny what Rand [Stoneburner] is saying is totally correct. I’m sorry somebody somewhere said things are screwed up and we need more of this or that... the condoms and all this. But I’m sorry it was already functioning there [Ugandan seroprevalence decline underpinned by reduction in multiple partnership]. And somebody was continuing...pressing the alarm saying okay look at this data from Uganda from here or there and I’m sorry that wasn’t the truth (former UNAIDS official: 19/09/2011).

Having presented interview data, which appear to suggest that a reduction in multiple partnership explanation was misinterpreted as a strategy to emphasise increased condom uptake as *the* preeminent sexual behavioural

change reason contributing to Uganda's HIV seroprevalence decline, it is important to reiterate that the author is not endorsing this narrative that emerged during data collection. Although Rand Stoneburner, and other participants interviewed during data collection indicated that Ugandan data misinterpretation took place sometime between 1996 and 1997 the author, in the interests of transparency, must make clear that these claims require further empirical investigation. Further empirical research is needed to substantiate or repudiate the complex and political notions generated as part of this doctoral study. The notions outlined above are conceptualised by the author as essentially exploratory in nature which therefore demand further independent analysis and empirical verification in the future—such exploration and analysis could take place once this doctoral study is completed. In the interest of good academic practice, please note that individual participants were given the right to reply to the highly personalised claims outlined above, however no responses were received by the researcher.

#### 5.6 Discussing the competition over Ugandan behavioural evidence amongst HIV/AIDS experts

Findings suggest that HIV/AIDS experts involved with the development of SGS competed amongst each other to legitimise, and discredit, contrasting sexual behavioural change explanations that could account for Uganda's HIV decline of the early to mid-1990s. It was discovered that certain HIV/AIDS experts aligned themselves to either a condom-based or a partnership reduction-based explanation that emerged from the analysis of Ugandan data sources. Importantly, the contested data sources, used to advance formative behavioural change explanations for Uganda's HIV decline, were the same data sources presented at the 1997 Nairobi workshop which helped support the introduction of SGS namely:



- 300 small-scale sociological surveys reviewed by Tom Barton, an anthropologist under the instruction of Michel Caraël, the former head of HIV prevention within UNAIDS.
- Two population-based surveys of sexual behavioural change conducted in Uganda in 1989 and 1995.

Therefore, it was important for this chapter to examine the competition surrounding the contested Ugandan data sources, and the influence of this competition upon the evidence used to support the development of SGS itself. Data presented in this chapter illustrate how interviewees involved with the framing of Uganda's HIV 'success' story aligned themselves according to two competing explanations for Uganda's HIV seroprevalence decline (both of which could have conceivably informed subsequent HIV/AIDS prevention policy advanced by UNAIDS from 1996 onwards). This raises important questions about why an increased condom uptake became *the* dominant explanation for Uganda's HIV seroprevalence decline in subsequent policy discussions, UNAIDS documentation and journal articles in the mid to late-1990s.

Interview data point to three factors that appear to have influenced which explanation came to dominate subsequent HIV policy development. First, claims were made about disciplinary differences between two key figures involved in competing interpretations of Ugandan data. Claims were advanced concerning the limitations of explanations favoured by scientists with an epidemiological or biomedical background. The construction of Rand Stoneburner as being poorly equipped to explain Ugandan sexual behavioural change data can be conceptualised as a discrediting technique intended to undermine support for his favoured explanations (i.e. a reduction in multiple sexual partners). This discrediting strategy has arguably been an important and overlooked element of the broader competition between HIV/AIDS experts, who attempted to frame their respective sexual behavioural change explanations as preeminent in the mid to late-1990s. The finding that an epidemiologist was not able to advance an

explanation, that could account for Uganda's HIV decline, is surprising as biomedical and epidemiological understandings of HIV/AIDS were dominant during the early to mid-1990s. One would expect that greater analytical significance would have been given to Stoneburner's explanation as the competing explanation, advanced by Michel Caraël, a socio-behavioural scientist, emerged when behavioural and social scientific approaches (which relied on mainly qualitative based data) were beginning to disseminate in HIV/AIDS policy networks.

Interview data also point to the importance of policy entrepreneurship within the global HIV/AIDS policymaking network and the ability of one expert, Michel Caraël (the former head of HIV prevention within UNAIDS) to function as a policy entrepreneur. Data have been presented which strongly suggest that Michel Caraël, underpinned by his reputation for socio-behavioural expertise, and his close working relationship with Peter Piot, the former director of UNAIDS, was highly influential in securing acceptance of the increased condom uptake explanation as the primary reason for Uganda's HIV decline. Finally, claims have also been presented concerning the purported misinterpretation of Ugandan data by Michel Caraël in order to strengthen the case for increased condom uptake as the explanation favoured for Uganda's HIV seroprevalence decline. Several participants, from both Genevan and Ugandan contexts, outlined their understandings of the purported Ugandan data misinterpretation. They elucidated that the interpretation, and analysis of, Ugandan evidence used to support SGS (and explanations of the Ugandan HIV decline) was a complex process, whilst acknowledging that increased condom uptake may not have been a wholly valid explanation that could account for the Ugandan HIV 'success' story.

## 5.7 Chapter summary

This chapter examined competing explanations for the Ugandan HIV 'success' story and how HIV/AIDS experts, involved with the analysis of Ugandan behavioural evidence attempted to legitimise either an increased

condom uptake, or a reduction in multiple partnership explanation, as *the* preeminent factor that could account for Uganda's HIV seroprevalence decline. It was ascertained that HIV/AIDS experts were involved in a highly contested process of trying to make the case for competing explanations for Uganda's HIV decline. The alignment process of HIV/AIDS experts, to each competing sexual behavioural change explanations, was framed by certain participants as highly divisive which led to significant levels of epistemic conflict within global HIV/AIDS policymaking networks. This chapter has highlighted that increased condom uptake became *the* accepted explanation for Uganda's HIV seroprevalence decline, as reflected in UNAIDS policy documentation and peer-reviewed publications in the mid to late-1990s (UNAIDS: 1998a; UNAIDS: 1998b; Asiimwe-Okiror et al: 1997). Whereas, a reduction in multiple partnership explanation, which came about due to increased awareness of HIV/AIDS and communication amongst Ugandans, did not appear to inform UNAIDS policy documentation or peer-reviewed journals in the same time period. Indeed, it was noted that the reduction in multiple partnership explanation was not widely disseminated until 2004 in the journal *Science*.

While this chapter examined the contested manner in which HIV/AIDS experts competed over Ugandan evidence, it did not examine the underlying reasons that contributed towards HIV/AIDS experts competing amongst each other within HIV/AIDS policymaking networks. Nor did it examine the political and institutional context, within which SGS and its evidence-base emerged, and the influence of political and institutional context change upon the evidence/SGS policy relationship. In reaction to the findings presented within this chapter, most notably the claim of Ugandan data misinterpretation, it is required to examine the broader political and institutional environment within which SGS emerged and their influence upon the Ugandan evidence used to support the introduction of SGS and the subsequent development of HIV prevention policy in the 1990s.

## CHAPTER SIX: Examining institutional and political context adaptation and the competing behavioural change explanations

### 6.1 Introduction to chapter

The previous chapter highlighted that certain HIV/AIDS experts competed over two behavioural change explanations that could account for Uganda's HIV prevalence decline of the 1990s. It explored the influence of disciplinary bias, policy entrepreneurship and claims of data misinterpretation as elements of a competition over contrasting behavioural change explanations, noting that an increased condom uptake explanation influenced the development of HIV prevention policy more directly than a partnership reduction explanation. While the previous chapter explored the competition amongst HIV/AIDS experts, it did not examine the broader institutional and political context within which the competition over Ugandan behavioural evidence occurred. Nor did it examine adaptations in the political and institutional context upon the competing behavioural change explanations that were advanced by HIV/AIDS experts in the mid to late-1990s. It is widely acknowledged that political and institutional contexts can influence policy development and how evidence gets synthesised into subsequent policy output (Hutchinson et al: 2011; Bowen & Zwi: 2006). Therefore, it is necessary to examine how the broader institutional and political context, which surrounded the competition amongst HIV/AIDS experts, influenced the competing behavioural explanations by those involved with the development SGS, formative accounts of Uganda's HIV decline and the development of global HIV prevention policy in the 1990s. Via an exploration of the institutional and political context, this chapter will facilitate the thesis to examine the contested explanations for the decline in HIV prevalence in Uganda in greater analytical detail and the role of evidence in the development of global HIV prevention policy in the 1990s.

## 6.2 The emergence of competing behavioural change explanations and the institutional transition from GPA to UNAIDS

To facilitate an analysis of institutional and political context adaptation upon the competing Ugandan behavioural change explanations that could account for the decline in Ugandan HIV prevalence, it is required to introduce an overarching finding that appears to have influenced the movement of the condom-based, and the partnership reduction-based explanations, within global HIV/AIDS policymaking networks. Importantly, the emergence, and analysis of, the contested Ugandan data sources used to support the development of SGS, and explanations for Uganda's HIV decline, arose when a significant institutional change took place within the United Nations (UN) political system in the mid-1990s. In the year 1995, the GPA, a WHO institution mandated to direct and coordinate the global fight against HIV/AIDS shut down—having operated from February 1987. In its place, on January 1<sup>st</sup> 1996, UNAIDS was launched under the leadership of Peter Piot, the first Executive Director of the newly formed UN institution. Significantly, the closure of GPA in 1995, and the launch of UNAIDS in 1996, resulted in a major policy shift in the approach to global HIV/AIDS prevention.

It is noted by Knight (2008), that GPA had adopted a biomedically focused approach to global HIV/AIDS prevention, which donors had expressed concern about as a strategy to mitigate the HIV/AIDS epidemic at the global level (Knight: 2008: pp. 18). Furthermore, it is claimed that GPA had adopted a “one-size-fits-all blueprint to countries when developing national AIDS plans” (Knight: 2008: pp. 18). This standardised approach to HIV/AIDS, it is argued, did not meet the need for culturally sensitive plans and effective HIV/AIDS programmes (Knight: 2008: pp. 18). The notion that GPA had adopted a mainly biomedical approach to global HIV/AIDS prevention was raised by Barnett & Whiteside (2002). It is claimed that GPA was medically and epidemiologically driven which adopted a short-term and conceptually restricted fire-fighting perspective on experience of other, more explosive,

and short-wave infectious disease epidemics (Barnett & Whiteside: 2002: pp. 23).

When UNAIDS was launched in 1996 it thus attempted to advance an expanded approach to global HIV/AIDS prevention which was broad-based and multisectoral, incorporating HIV/AIDS into all aspects of human development and economic planning (Knight: 2008: pp. 42). Departing from GPA's biomedical approach to HIV/AIDS prevention, UNAIDS intended to pursue a multisectoral approach to mitigate HIV/AIDS at the global level from 1996 onwards. According to Harman (2012), multisectoralism pertains to the inclusion of multiple actors—state, non-state, community-based, globally-based, regional, public, and private—in the delivery and decision-making of healthcare initiatives. The purpose of this integration is to acknowledge the inter-relationship of health with multiple sectors of state-based activity, development and inequality; and to increase participation and accountability within global health (Harman: 2012: pp. 47). The adoption of a multisectoral approach by UNAIDS thus shifted the biomedical paradigm that had previously defined global health governance whilst positioning health as a development objective and practice (Harman: 2012: pp. 47). The formal adoption of a multisectoral approach to HIV/AIDS prevention by UNAIDS is stated within UN Economic and Social Council (ECOSOC) Resolution 1994/24 Section 3.10:

An important function of the programme will be to strengthen national capacities to plan, coordinate, implement and monitor the overall response to HIV/AIDS. The participation in the programme of six organizations of the United Nations system will ensure the provision of technical and financial assistance to national activities in a coordinated multisectoral manner (ECOSOC Resolution 1994/24: 3.10).

The notion of multisectoralism is also emphasised within the objectives of Resolution 1994/24 which highlighted the need for UNAIDS to:

Promote broad-based political and social mobilization to prevent and respond to HIV/AIDS within countries, ensuring that national responses involve a wide range of sectors and

institutions (ECOSOC Resolution 1994/24: I. Objectives: Objective E).

An historical account that describes the institutional transition from GPA to UNAIDS, and the policy transition from clinically-focused HIV prevention strategies to multisectoral HIV prevention strategies, was advanced by James Guwani, a UNAIDS Strategic Information Adviser:

UNAIDS was basically created to coordinate the UN around HIV programming because people felt it [HIV/AIDS] was a clinical disease when we had it at the Global AIDS Programme [GPA] at WHO [from 1987 – 1995]. They were looking at the clinical dimensions...and when we [UNAIDS] started realizing that it was no longer just a clinical condition, there was a need to have a more multisectoral approach to deal with it [HIV/AIDS]...and therefore the creation of an organisation that actually could bring in all the other agencies that were non-clinical: UNDP, UNCHR, UNICEF, ILO and all those other agencies aboard because then WHO did not have the...to be able to effectively interact with the external...the non-clinical actors (Guwani: 31/01/2012).

As is emerging, the institutional transition from GPA to UNAIDS resulted in the introduction of a new approach to global HIV/AIDS prevention which attempted to depart from older, biomedically informed, HIV prevention strategies that had been implemented by the WHO's GPA. Having introduced the idea of institutional change within the UN political system in the mid-1990s, it is now required to examine how the transition from biomedical-based HIV prevention approaches to multisectoral HIV prevention approaches affected the competing Ugandan behavioural change explanations. The two following sections will outline two themes that emerged from data analysis. First, the theme that the partnership reduction explanation did not appear to align with the prevailing political and institutional transition towards the multisectoral HIV/AIDS prevention agenda as advanced by UNAIDS from 1996 onwards. Second, the theme that the partnership reduction explanation presented UNAIDS with possible funding dilemmas, as this explanation did not necessitate an extensive mobilisation of financial support from UNAIDS, and other external actors, to prevent HIV transmission.

### 6.3 Partnership reduction in Uganda and UNAIDS' multisectoral HIV/AIDS prevention approach

Interview data suggest that the partnership reduction explanation, which Rand Stoneburner and Daniel Low-Beer claimed could account for Uganda's HIV prevalence decline, did not align with UNAIDS' multisectoral approach to global HIV/AIDS prevention. According to Stoneburner & Low-Beer, their explanation indicated that partnership reduction, which was catalysed by an endogenous process of increased HIV awareness and communication amongst Ugandans, occurred without the implementation of UNAIDS' multisectoral approach. Their explanation, it is claimed, was potentially problematic for UNAIDS as it was attempting to implement its multisectoral approach to global HIV/AIDS prevention, an approach which wanted to emphasise the use of condoms to prevent the transmission of HIV via the engagement of multiple stakeholders and broad-based social mobilisation. By attempting to advance the partnership reduction explanation, Stoneburner claimed that the idea of a Ugandan-based HIV prevention initiative (which did not require a UNAIDS led multisectoral HIV response or the need to advocate for funds to promote the use of condoms) was met with scepticism by senior-level officials within UNAIDS:

It's just ridiculous that somehow this [Ugandan] population had done something on its own without an external product like a condom that interrupted [HIV] transmission. If it's condoms it's okay. That's a biomedical product. But here they had spontaneously changed their behaviour...in threat to this public health disaster [HIV/AIDS]. That's one explanation...and that interfered with their [UNAIDS'] whole basis...for a need to bring the UN and the World Bank and all these people in together to make bigger pieces of pie (Stoneburner: 05/08/2011).

The claim advanced by Stoneburner was echoed by Daniel Low-Beer, an epidemiologist involved with the analysis of Ugandan data in the mid to late-1990s. Low-Beer asserted that the partnership reduction explanation conflicted with UNAIDS' multisectoral approach to global HIV/AIDS prevention, whilst acknowledging that the reasons contributing towards



Uganda's HIV decline were brought about, and owned, by the Ugandan Government:

Well who owned it? It was a Ugandan public health programme a pretty direct one. It wasn't a long-term multisectoral development response by the UN partners. So that fundamentally...there was a big institutional difference it was a direct country programme to fight AIDS...but it was different than what was being promoted at the beginning...the type of response that UNAIDS was built around in 1996 (Low-Beer: 06/12/2011).

It is also claimed by Daniel Low-Beer, an epidemiologist involved with the analysis of Ugandan data in the mid to late-1990s, that the partnership reduction explanation, and the evidence supporting the explanation itself was possibly "forgotten" (Low-Beer: 06/12/2011) by UNAIDS as it did not align with its multisectoral approach to global HIV/AIDS prevention:

Well the evidence for me was forgotten...because UNAIDS was not about that basic public health response at the beginning. It was the development response a long-term cycle and it was based more on [HIV/AIDS] modelling. And it had some strengths, I mean there's no doubt it had some strengths, but it was quite an institutional change (Low-Beer: 06/12/2011).

Describing the partnership reduction explanation, and how it challenged UNAIDS' development centered and multisectoral response to HIV/AIDS further, Daniel Low-Beer, an epidemiologist involved with the analysis of Ugandan data in the mid to late-1990s, raises the idea that a reduction in partnership explanation did not "filter through" UNAIDS when it was formed in 1996 citing political reasons:

When Peter Piot [first Executive Director of UNAIDS] came in when he was in Uganda saying this is a long-term response...it wasn't something that was going to happen quickly...it was something that was going to be 10, 15 years as we change development. But the fact is those countries...with some support from the outside...not driven with a large numbers of partners [external donors] could fight AIDS. And that institutionally didn't filter through that new organisation [UNAIDS]. It wasn't part of its rationale for creating something new...but that's

politics. I mean politics is part of...there's always going to be that political filtering (Low-Beer: 06/12/2011).

The notion that Peter Piot, the former Executive Director of UNAIDS, may not have acknowledged the partnership reduction explanation, emerging from the analysis of Ugandan behavioural data sources, was also posited by Rand Stoneburner, a former GPA/UNAIDS epidemiologist:

But it's very interesting because Peter [Piot] didn't embrace this [partnership reduction explanation] and it was also because I think he'd already convinced the whole UN community to come in and create this mammoth organisation with its infusion of resources...which is good. But it may have been difficult for him to come back to them and say...oh by the way we've got a 60% decline in infections coming out of Uganda and people would say well how did that happen? It's not because of our investment? Oh it's just spontaneous behaviour change? This is happening in every [HIV] epidemic in the world you know? I'm speculating here...but I have a feeling that those things were going around in his head (Stoneburner: 26/10/2011).

Stoneburner provided a detailed description of UNAIDS' multisectoral response to HIV/AIDS, the narrative below outlines the dominant policy discourse of multisectoralism and its development centered approach. The data below also appear to indicate that there was a broad commitment by UNAIDS to not focus on HIV/AIDS as a narrowly defined biomedical policy problem (which GPA had done between 1987 – 1995):

We need to bring the entire UN together and focus, not on just the dynamics of HIV and behaviour, treatments, or health issues [former GPA prevention approach]...but we have to fix the whole kit and caboodle of development. We have to go for women's rights, we have to address stigma...but all these other dimensions that have now become the columns or the strategies for the development agenda. If you look at UNAIDS they've got so many things out there (Stoneburner: 26/10/2011).

A description relating to how GPA was ostensibly "battling with" (Stoneburner: 26/10/2011) other UN organisations, prior to its closure in 1995, and how scientists, who attempted to explain Uganda's HIV seroprevalence through behavioural data, was advanced by Stoneburner. The data below appear to indicate that the sexual behavioural change that

occurred within Uganda in the early to mid-1990s took place without UNAIDS' multisectoral response and the infusion of finance from external donors:

GPA was battling with the other UN organisations. And then all the scientists were down....showing the [HIV] decline here [in Uganda]. We've got this...behavioural surveillance, which is in its infancy it's not very good, but wow look something's going on...but what it was telling you, potentially, was that whatever had happened without UNAIDS without this massive organisation and all this infusion (Stoneburner: 26/10/2011).

The assertions above appear to suggest that the partnership reduction explanation, which emerged during the closure of GPA and the establishment of UNAIDS, was not actively internalised by UNAIDS as it may not have aligned with the prevailing institutional and political context and the transition towards multisectoralism. It appears that the endogenous process of sexual behavioural change, which was possibly brought about by Ugandans communicating about the threat of HIV, led to declining HIV trends within the country (at least according to Stoneburner and Low-Beer's data analysis). However, this finding, which was initiated by Ugandans did not involve the newly developed multisectoral approach that UNAIDS was aiming to implement (and aiming to mobilise financial resources for) when it was created in January 1996. It therefore seems possible that the explanation of behavioural change, advanced by Stoneburner and Low-Beer, was perhaps working against UNAIDS' development-centered and multisectoral global HIV/AIDS prevention strategy—an approach which aimed to promote the use of biomedical products, including condoms, to help reduce the transmission of HIV at the global level.

This finding is surprising as it could be argued that the partnership reduction explanation, which came about via oral communication within the Ugandan population, could have worked with UNAIDS' multisectoral HIV prevention approach. This idea can be tentatively advanced as multiple sectors, state and non-state actors could have worked together under the rubric of multisectoralism to promote HIV/AIDS awareness campaigns (via broad-

based social mobilisation) which highlighted the importance of domestic communication in fighting HIV/AIDS. Acknowledging that the partnership reduction explanation could have conceivably complemented UNAIDS' multisectoral HIV prevention policy agenda, it is important to outline additional reasons which perhaps slowed the partnership reduction explanation from informing subsequent HIV/AIDS prevention policy output in the mid-1990s.

#### 6.4 Partnership reduction and UNAIDS funding implications

A theme which may account for the partnership reduction explanation not informing HIV/AIDS prevention policy relates to funding implications which, according to certain participants, would have influenced UNAIDS' institutional financial strategies in the mid-1990s. It was noted above that the partnership reduction explanation highlighted the principal role of communication within the Ugandan population in helping to prevent the transmission of HIV. This prevention strategy, it is claimed, did not require external investment from UNAIDS or its newly developed multisectoral HIV/AIDS prevention policy approach. Commenting upon how the partnership reduction explanation was viewed by other HIV/AIDS experts, Rand Stoneburner asserted that "there was just a lot of negativity to it people said it's great [partnership reduction explanation] but it will hurt funding" (Stoneburner: 05/08/2011). While Stoneburner claimed that certain HIV/AIDS experts within UNAIDS "believed" (Stoneburner: 05/08/2011) the partnership reduction explanation, it was asserted that UNAIDS' multisectoral HIV/AIDS prevention policy agenda was influencing the perceived credibility of this explanation in HIV/AIDS networks:

People said well we believe this [partnership reduction explanation] but...you're in the big shit now because you've got all these UN agencies that are on-board. The UN agenda at that time was this multisectoralism...which I never could figure out what it was back then. But it was that you can not respond to a health problem by just treating it as a health problem. You have to deal with all the other intricacies, civil society, you have to remove discrimination, you have to remove all the obstacles to

access to education. So they took the whole development agenda and tried to pile it on...insert it into this public health disaster [HIV / AIDS] (Stoneburner: 05/08/2011).

The possible implications of the partnership reduction explanation upon UNAIDS' multisectoral approach, and the potential consequences for those who would ultimately receive funding from UNAIDS, in both HIC and LIC contexts, was raised by Rand Stoneburner:

I even had people...scientists in Uganda and from the US who said this is really bad news...what is this going to be doing to our funding? Yeah...I heard that from several people. But I said what do you mean? But you can understand these people it's their lifeblood...a lot of agendas (Rand Stoneburner: 24/03/2013).

It was also asserted that attempts to promote the partnership reduction explanation challenged an element of UNAIDS' multisectoral approach, namely, UNAIDS' desire to unify multiple development partners in order to increase financial resources to mitigate HIV / AIDS at the global level:

So when you tried to position spontaneous indigenousness behaviour modification up against the big boys...big pharma, big drugs and big development...I think the die had already been cast for all of these resources coming together...new structure and it was really hard to get it out after that (Rand Stoneburner: 05/08/2011).

Notions relating to the global policymaking implications of Uganda's HIV seroprevalence decline were advanced by Stoneburner. The narrative below describes the UN's attempt to unify under the multisectoral approach to take advantage of the Ugandan HIV decline, which was described by Stoneburner as a "hot piece of pie" (Stoneburner: 05/08/2011). This metaphor alludes to the notion of the formative signs of HIV seroprevalence decline being an attractive, unfolding narrative that invited external actors to capitalise upon:

...lots of institutional politics and then I got the feeling that UNDP, and UNCIEF, all of them wanted...World Bank they all came in with their big guns and said this is how you do it [address HIV / AIDS globally via multisectoralism]. You know what, this was hot piece of pie [the Ugandan HIV decline] this

was hot...if they [external UN actors] could catch on to this comet they could...bring together all of the agencies to work as one instead of this disjointed band of folk and country that were kind of sniping at each other (Stoneburner: 05/08/2011).

A sub-theme regarding the funding implications of the Ugandan HIV 'success' story was noted during data analysis, namely, the potential funding implications of the HIV decline upon Ugandan resource mobilisation from external donors. Concerns about the implications of the Ugandan HIV decline, and its influence upon domestic funding were noted by Joshua Musinguzi, former head of the AIDS control programme within the Ugandan Ministry of Health. The data below appear to suggest that Musinguzi, was concerned about the influence of the Ugandan HIV decline upon domestic funding within Uganda. It could be asserted, as a recipient of financial support from external donors, that there were genuine concerns surrounding the Ugandan 'success' story upon external funding streams—especially within the Ugandan Ministry of Health. Musinguzi's narrative indicates that there was a joint concern about the HIV decline influencing domestic funding and a broader public health issue of sexual behavioural complacency which could lead to increasing rates of HIV infection:

Especially at that time [1995 – 1996] and the concern was mainly twofold one was what would be the implication on resource mobilisation? And then capacity if you're telling the world that the [HIV/AIDS] epidemic seems to be contracting in this part of the world will people have the same interest in funding your programmes? The second question was the issue, the potential issue of complacency—will people get complacent? (Musinguzi: 27/01/2012).

Two Ugandan Ministry of Health officials also commented upon the institutional transition from GPA to UNAIDS, and the associated shift from GPA (which was depicted as a technical-based international organisation) to UNAIDS (which was depicted as a more politically-based international organisation). Elizabeth Madraa, the former manager of Uganda's AIDS control programme, claimed that:

GPA was very strong at the beginning and of course when UNAIDS came in there was no money to transfer to UNAIDS for support. UNAIDS was not technical. UNAIDS has been really political it was not really technical...it wanted the emphasis on multisectoral. But in the multisectoral approach unless you set the system of coordination you find yourself in the problem because the other sectors have never understood why they should participate in the HIV (Madraa: 20/01/2012).

Alex Opio, assistant commissioner for national disease control within the Ugandan Ministry of Health, also claimed that it was a core strategy of UNAIDS to concentrate on resource mobilisation when the institution was formed in 1996. The data below indicate that UNAIDS' concentration on multisectoralism led to the institution being framed as less technical and more political than its predecessor GPA:

UNAIDS came in and their focus...one they were saying that they wanted to do resource mobilisation say their focus was a little bit different...multisectoral and they were less technical – I mean...epidemiological aspect very weak, very, very weak. So for sure there was some loss period of time [sic] because of that transition from WHO to UNAIDS. So down the road then WHO started again reactivating some of the departments which they had given up which they thought UNAIDS would do – they started reactivating (Opio: 14/ /02/2012).

The data above suggest that the partnership reduction explanation, which could have been constructed as a positive development in relation to HIV/AIDS prevention, was possibly framed as a problematic finding as it held the potential to impact upon the process of resource mobilisation, and subsequent resources distribution, by UNAIDS when it was formed in 1996. This finding is somewhat paradoxical as the data above illustrate a counterintuitive notion, namely, the 'problem of Ugandan success' (as the seemingly positive evidence of decreasing HIV rates, via oral communication and partnership reduction within the country were actually viewed as potentially problematic, in relation to funding mobilising at the global level, and funding distribution at the national level by certain HIV/AIDS experts in the mid-1990s). Acknowledging that there was a possible 'solution' to the prevention of HIV, via oral communication, a solution that did not require the broader UN system, multisectoralism and the infusion of external

financial support, it can be cautiously posited that the partnership reduction explanation faced considerable difficulty in establishing itself as a credible explanation for the Ugandan HIV seroprevalence decline during the mid to late-1990s. This difficulty can be attributed to the partnership reduction explanation failing to align with the prevailing political and institutional climate when UNAIDS was launched in 1996, and how this finding jarred with a multisectoral HIV/AIDS prevention strategy that was formally established in UNAIDS' founding ECOSOC resolution in 1994.

### 6.5 UNAIDS' decision-making structure and senior officials' opinions on competing behavioural explanations

Interview data have provided an examination of the institutional transition from GPA to UNAIDS, adaptations in institutional approaches to global HIV/AIDS prevention, and how the partnership reduction explanation may not have aligned with the prevailing institutional/political context and the transition to multisectoralism in the mid-1990s. However, the chapter has yet to examine the internal decision-making structure within UNAIDS, and how senior-level officials conceptualised the competing behavioural change explanations advanced by HIV/AIDS experts involved with the development of SGS, and formative accounts of Uganda's HIV seroprevalence decline of the 1990s.

The two following sections will present findings that examine these factors in order to establish how decision-makers' institutional position within UNAIDS, and decision-makers' 'loyalty' to UNAIDS itself influenced the significance afforded to the competing behavioural change explanations. These findings are advanced in order to demonstrate the salience of context-specific institutional factors that appear to influence the relationship between evidence and policy within global HIV/AIDS policymaking networks.

Interview data highlight that participants' institutional position within UNAIDS contributed towards the significance afforded to the competing behavioural change explanations. Individuals who were institutionally more



senior within UNAIDS possessed the ability to promote their explanation for the HIV prevalence decline more efficiently than those further down UNAIDS' decision-making hierarchy. This notion was emphasised by Michel Caraël, the former head of HIV prevention within UNAIDS. During interview, Caraël critiqued the idea that Elizabeth Pisani, a less-senior UNAIDS consultant, was able to formulate novel HIV/AIDS policy within UNAIDS/WHO during interview. Caraël maintained that "the credibility to push ideas" (Caraël: 20/09/2011) was determined by enjoying a senior institutional position within UNAIDS, which Elizabeth Pisani did not possess:

She [Elizabeth Pisani] was a consultant she wouldn't have an institutional position that would allow her—she was never in a position in UNAIDS or WHO. She was engaged for the workshop in Nairobi...and I hired her for, I don't know, 20 days you know? So we were using her but more to write documents like reports and things like that. But I mean she would come from another planet...so she would not have any credibility to push ideas (Caraël: 20/09/2011).

The salience of "belonging" (Caraël: 20/09/2011) to an international institution, and how Elizabeth Pisani lacked this sense of institutional belonging, was advanced by Caraël:

I think she's [Elizabeth Pisani] probably not highlighting this but it's important. Because unfortunately if you don't belong to such international institutions [UNAIDS] you cannot produce the guidelines...the normative guidance to countries...I mean whether Pisani would have been there or not it wouldn't have made any difference (Caraël: 20/09/2011).

Caraël's claim relating to Elizabeth Pisani's function as a writer, and her lack of institutional standing, was reinforced by Daniel Tarantola, a former senior employee of the GPA/former senior policy advisor to the Director General of the WHO:

Elizabeth Pisani was not a methodology developer. I mean she sort of presents herself as an anthropologist. She was a scribe, she was a writer, a rapporteur. And she would go out there with Michel Caraël and others...reports to which she would give

shape because of the quality of her writing. No, the methodology development came from a variety of sources at the same time. But while she was indeed shaping reports and presenting report outcomes in a clear way...I don't think it would be fair to give her the credit (Tarantola: 27/10/2011).

Michel Caraël explained his own institutional function in developing SGS and broader HIV/AIDS policy during interview. Caraël framed himself as a leader within global HIV/AIDS policymaking networks in the mid to late-1990s, emphasising that he “ordered” (Caraël: 20/09/2011) Tom Barton, an anthropologist, to conduct a review of Ugandan sexual behavioural change data. As noted in the chapters above, the Barton review was important in understanding Ugandan sexual behavioural change and how it helped to develop formative behavioural explanations that could account for Uganda's HIV seroprevalence decline. Michel Caraël authoritatively remarked that “I was the one who ordered him to do it” (Caraël: 20/09/2011).

Caraël also claimed that it was his role to appraise the Barton review prior to its findings informing subsequent HIV policy stating that “it was published and appraised by myself in UNAIDS and published at the time” (Caraël: 20/09/2011). The interview data above thus appear to indicate that Caraël was an institutionally important decision-maker within UNAIDS who was able to tell subordinates to perform policy-related tasks in a top-down fashion. Furthermore, his ability to appraise data sources and to publish evidence within UNAIDS himself, further illustrate his centrality within UNAIDS' compact global HIV/AIDS policymaking networks. It could be argued that Caraël possessed the requisite institutional power to promote the increased condom uptake explanation which, in turn, permitted it to be perceived as a more credible explanation that could account for the Ugandan HIV seroprevalence decline of the early to mid-1990s—especially within the institutional context of UNAIDS.

Distinct from Michel Caraël's institutionally senior position within UNAIDS, the following interview data suggest that Rand Stoneburner, a former GPA/UNAIDS epidemiologist, did not possess the requisite institutional

position (or institutional power) to advance the partnership reduction explanation within UNAIDS in the mid to late-1990s. A primary obstacle to the partnership reduction explanation failing to inform HIV policy, in the mid to late-1990s, was the termination of his employment during the institutional transition from the GPA to UNAIDS (occurring between 1995 – 1996). Stoneburner claimed that Peter Piot, the former Executive Director of UNAIDS, terminated his employment during the institutional transition:

Peter Piot...most of the people at GPA were let go they found other jobs. He made sure that I was not given a job. I was the only one who was sort of summarily fired (Stoneburner: 24/03/2013).

Stoneburner's claim about his employment being terminated during the GPA/UNAIDS transition, was echoed by Manuel Carbello, the former chief of behavioural research at the WHO's GPA. The data also indicate that Stoneburner's partnership reduction explanation was conceptualised as "vital information" by Carbello which may have been disregarded by UNAIDS in the mid to late-1990s:

Rand [Stoneburner] had to leave [GPA & UNAIDS] as well so I think that in a sense you could say that intentionally, or unintentionally, decisions were taken to disregard vital information...and I think that it is no accident that a few years ago UNAIDS has had to backtrack on its statistics (Carbello: 20/9/2011).

A sub-theme which relates to the requirement of less senior HIV/AIDS experts to not counteract senior-level management within UNAIDS, in order to 'survive' in the institution itself, was noted during data collection. A former UNAIDS official indicated that Stoneburner's partnership reduction explanation worked against the senior-level management position to global HIV prevention within UNAIDS in the mid-1990s—namely multisectoralism. The data below appear to suggest that Stoneburner's failure to comply with UNAIDS' senior-level management position, by pursuing a partnership reduction explanation, contributed to Stoneburner not enduring the GPA to UNAIDS institutional transition:

In these big [UN] bureaucracies the way we function is...we have what is called senior level managers. So you have in the department a senior level management team...and the others are those like us who do the daily work...and who are not listened to you know? So we just do our work...because that's the way you survive in this organisation [UNAIDS]...you're not allowed to go and counteract the senior level management position (former UNAIDS official: 19/9/2011).

It could be advanced that attempts to promote a partnership reduction explanation, that could account for the Ugandan HIV decline, potentially worked against more senior-level decision-makers within UNAIDS, and their attempt to promote a multisectoral HIV/AIDS prevention policy approach at the global level. In reaction to the findings presented above it can be suggested that the partnership reduction explanation may not have been afforded as much institutional significance within UNAIDS in comparison with the increased condom uptake explanation. It can be argued that the possession of a senior institutional position within UNAIDS was key in facilitating the use, or non-use, of the competing sexual behavioural change explanations. Findings above also highlight the importance of working with, rather than against, the prevailing policy positions of senior-level management within UNAIDS in order to 'survive' within the institution itself.

A sub-theme, which relates to the idea that certain interpretations of Ugandan evidence were not internalised by senior-level management within UNAIDS in the mid-1990s, pertains to the notion of institutional loyalty. Claims were advanced by certain participants who maintained that failure to function in an institutionally loyal manner, during the transition from GPA to UNAIDS, and its preconceived multisectoral HIV/AIDS prevention policy agenda, resulted in dismissal. Data below appear to suggest that Peter Piot, the former Executive Director of UNAIDS, continued to employ HIV/AIDS experts who supported UNAIDS' multisectoral HIV/AIDS prevention policy agenda from 1996 onwards. The narrative below provides an explanation of Rand Stoneburner's dismissal during the GPA/UNAIDS transition and how

other, institutionally loyal, HIV/AIDS experts were granted ongoing employment from Peter Piot, the former Executive Director of UNAIDS:

It caused a lot of bitterness...and there are people who were I would say loyal WHO HIV/AIDS people who were kicked out like Rand Stoneburner. Others, for one reason or another were kept on board - Michel Caraël and a lot...people were kept on board. And some disagreed with Peter Piot's policies or others they left between 1995 and 1996 and 2000 they disappeared...went to work with other people (former UNAIDS official: 19/9/2011).

The notion that Peter Piot, the former Executive Director of UNAIDS, continued the employment of institutionally loyal HIV/AIDS experts was also advanced:

Kept on board were people who...it's like any institution...kept the thinking and loyalty to Peter Piot and his thinking. That's how these institutions function you know? 100, 200, 300 people...and then it grew up to several hundred across the world...that's how these institutions function (former UNAIDS official: 19/9/2011).

The sub-theme of institutional loyalty was elaborated even further, suggesting that HIV/AIDS experts who produced, and attempted to disseminate, evidence that countered the institutional direction of UNAIDS may not be given employment "loyalty means, you know, the others who disagreed...they'll escape or they'll never be hired" (former UNAIDS official: 19/9/2011). An additional facet of institutional loyalty relates to the notion of "protective" relationships between senior-level decision-makers within UNAIDS. This was emphasised by Rand Stoneburner when discussing the process of Ugandan behavioural data interpretation. Stoneburner commented upon Michel Caraël's institutional relationship with Peter Piot claiming that "Michel [Caraël] is very protective of Peter [Piot] in all of this" (Stoneburner: 24/03/2013). Stoneburner also described the consequences if less senior decision-makers operating within UNAIDS challenged Peter Piot, the former Executive Director of UNAIDS, advancing a narrative including Bernhard Schwartländer, the former director for evidence, strategy and results within UNAIDS:

Stoneburner: Bernhard [Schwartländer] certainly was part of that network...and I think they all knew...at least Bernhard [Schwartländer] knew what happens if you stand up to Peter Piot...

*Interviewer: And what happens?*

Stoneburner: You don't fare well. Because he has his loyal - it's feudal. He has his loyal people in his world which is interesting...I don't think a lot of people ever trusted him. But I think he became much more...he was always on the political side and then became more and more political once he was up at that power level (Stoneburner: 24/03/2013).

#### *6.5.1 Views on the competing behavioural explanations by the former Executive Director of UNAIDS*

Interview data also suggest that Peter Piot, the former Executive Director of UNAIDS, appeared to be more receptive to an increased condom uptake explanation compared with a partnership reduction explanation. A greater degree of significance was apparently given to the condom uptake explanation, stemming from the perceived expertise of Michel Caraël, the former head of HIV prevention within UNAIDS, by Peter Piot. The data below appear to suggest that Rand Stoneburner had to depart UNAIDS in the mid-1990s, whereas, Caraël successfully transferred from GPA to UNAIDS which can be attributed to his perceived expertise by other, more senior decision-makers—including Peter Piot:

What happened between Michel [Caraël] and Rand [Stoneburner] GPA and UNAIDS is Michel Caraël was the guru of this thinking and was the one who Peter Piot kept on-board and Rand Stoneburner was kicked out in the butt (former UNAIDS official: 19/09/2011).

The notion that Michel Caraël's increased condom uptake explanation was synthesised more readily than the partnership reduction explanation was elaborated further by the former UNAIDS official. The data below indicate that the analysis of the Ugandan behavioural data sources, conducted by

Michel Caraël, informed institutional understandings of the Ugandan HIV decline within UNAIDS. When discussing the competing sexual behavioural change explanations, that could account for the Ugandan HIV seroprevalence decline, it was asserted that:

So this is what I know. Michel Caraël was the guru of Peter Piot and his voice was heard and he didn't listen to the others. So at the end of course, it was the data and truth from Michel Caraël that came across...his thinking was what went into the UNAIDS secretariat (former UNAIDS official: 19/09/2011).

The manner in which Peter Piot purportedly engaged with the partnership reduction explanation was raised by a former UNAIDS official. It highlights how certain forms of evidence can be strategically interpreted within an institutional decision-making context:

I think Peter Piot favoured or just wanted to look at...consider Michel Caraël's point of view...and pulled under...underplayed Rand [Stoneburner] and Daniel's [Low-Beer] findings. So you will always find this in any science. Interpreting things...that you will have people saying...okay this is the evidence and the other...It's not bad science...but we can't talk about it...or we don't have enough evidence to support...so they ignored or they didn't want to hear about it [partnership reduction explanation] (former UNAIDS official 19/9/2011).

The claim that Peter Piot, the former Executive Director of UNAIDS, did not personally synthesise the partnership reduction explanation, and how he purportedly downplayed this particular behavioural change finding was advanced by Rand Stoneburner, a former GPA/UNAIDS epidemiologist. The data below indicate that Rand Stoneburner appreciated that he was perhaps functioning in a naïve manner, in relation to the partnership reduction explanation—assuming that his finding of sexual behavioural change would automatically disseminate without issue during the institutional transition from GPA to UNAIDS:

Peter [Piot] wouldn't necessarily come to these meetings he'd have somebody else come to see what was going on. I didn't appreciate...I naively said god well everybody wants to hear

about this [partnership reduction explanation] but Peter Piot said...I forgot what the words were they said this is...what's going on in Uganda is not sufficient to...he was trying to downplay it as not that important. So he'd already been part of the politics that were developing this new organisation [UNAIDS] (Stoneburner: 26/10/2011).

This sub-section suggests that Peter Piot, the former Executive Director of UNAIDS may have been more receptive to the increased condom uptake explanation (as advanced by Michel Caraël) compared with the partnership reduction explanation (as advanced by Rand Stoneburner). The possible reasons which contributed towards this taking place relate to the perceived expertise of Michel Caraël by Peter Piot, and the idea that the condom uptake explanation aligned more directly with Peter Piot's multisectoral approach to global HIV/AIDS prevention (as condoms were a tangible biomedical product that UNAIDS could advocate for and subsequently distribute via the multisectoral approach at the global level). However, it is again important to state that the claims advanced by Rand Stoneburner and other participants represent their own views and cannot be independently verified.

Findings above also highlight that the partnership reduction explanation was not working with the prevailing institutional and political environment within UNAIDS (and the multisectoral global HIV/AIDS prevention approach advocated by Peter Piot). It could be argued that the failure to understand the implications of the partnership reduction explanation, within the context of major institutional and political change in the broader UN system, contributed to this explanation not being utilised to inform subsequent HIV/AIDS policy output by UNAIDS in the mid to late-1990s. The findings also indicate that the prevailing institutional and political context, and broader adaptations to the institutional and political context during the transition from GPA to UNAIDS, influenced the competing sexual behavioural change explanations. It can be argued that HIV/AIDS experts, who were more receptive to the evolving institutional and political climate between 1995 – 1996, and the need to facilitate the newly developed multisectoral HIV/AIDS prevention policy agenda, stood a better chance in



allowing their behavioural explanations to inform subsequent HIV policy output in global HIV / AIDS policymaking networks.

Findings have also highlighted that Michel Caraël, the former head of HIV prevention within UNAIDS, appeared to enjoy an institutionally close and productive working relationship with Peter Piot, the former Executive Director of UNAIDS. It has also been highlighted that Peter Piot listened to Michel Caraël which facilitated his particular views to influence the most institutionally senior decision-maker within UNAIDS. It appears that Michel Caraël was a central and institutionally powerful actor who can be confidently located in relation to influencing the process of Ugandan evidence interpretation within global HIV / AIDS policy networks. It can also be stated that senior-level decision-makers within UNAIDS operated in both a loyal and purportedly “feudal” (Stoneburner: 24/03/2013) fashion. While this decision-making behavioural is comparable to other international organisations, the protective nature of the close relationships between an elite of likeminded senior-level actors within UNAIDS, and their power to remove decision-makers who are not perceived as institutionally loyal, raises important questions pertaining to the relationship between evidence and policy within global HIV / AIDS policymaking networks.

## 6.6 Strategic management of Uganda’s HIV decline within UNAIDS

A theme relating to the strategic management of Uganda’s HIV seroprevalence decline by UNAIDS emerged from data analysis. Findings suggest that the emergence of Uganda’s HIV seroprevalence decline (which occurred during a period of institutional instability—i.e. the transition from GPA to UNAIDS) was cautiously approached by UNAIDS in 1996. This was emphasised by an HIV / AIDS official within the WHO. It was suggested that the timing to announce the Ugandan HIV seroprevalence decline was carefully selected by UNAIDS, as concerns existed about the behavioural evidence-base, which were revealing the HIV decline within the country. Indeed, it was asserted that there was a prevailing institutional concern to not announce a decline in HIV trends emerging from Uganda in case the

signs of decline were an artifact or the outcome of measurement bias. The emerging signs of decline coming from Uganda were compared, by the HIV/AIDS official within WHO, to that of a bomb exploding and the idea that the HIV decline itself presented UNAIDS with issues relating to its global advocacy role (and its need to mobilise financial resources to mitigate HIV/AIDS at the global level via political advocacy). It was also asserted that there were implications of Uganda's emerging HIV seroprevalence decline, and the potential consequences upon UNAIDS' institutional need to advocate for increased financing to address HIV/AIDS at the global level via multisectoralism.

This notion is significant as it introduces the idea that the Ugandan HIV decline, and the possible reasons that contributed towards the Ugandan 'success' story itself, may have influenced one of UNAIDS' key functions—namely its institutional role to advocate for increased funding to mitigate HIV/AIDS at the global level from the mid to late-1990s onwards. To acknowledge that there was an HIV/AIDS 'success' story emerging from Uganda, in the mid-1990s, could have been problematic for UNAIDS, as one of its core institutional functions was to advocate for greater financial mobilisation to mitigate HIV/AIDS via multisectoralism—which was a long-term development centered prevention approach (which thus required extensive external financial support to implement). Acknowledging that HIV/AIDS had been 'solved' within a sub-Saharan Africa country in the early to mid-1990s (possibly based on increased oral communication without UNAIDS and its long-term multisectoral approach) was potentially problematic as acknowledging this 'success' would have questioned UNAIDS' global HIV/AIDS prevention strategy, and its need to emphasise the growing problem of HIV/AIDS (in order to raise more financial support to fight HIV/AIDS globally).

Rand Stoneburner, a former GPA/UNAIDS epidemiologist, maintains that the emerging signs of HIV seroprevalence decline were unexpected and how there was a general consensus amongst UNAIDS decision-makers that this HIV decline should not have happened (as UNAIDS' multisectoral HIV

prevention policy agenda had yet to be implemented). Such a position was advanced as there had been an absence of external UNAIDS led multisectoral programmatic involvement within the country:

Then I came to WHO and we [Rand Stoneburner & Daniel Low Beer] started looking at Uganda and no one thought that anything would happen there because there hadn't been any formal programme...there was an AIDS programme but as far as what the intervention purist would say...well we [UNAIDS] haven't fully invested in our programme now (Stoneburner: 05/08/2011).

The findings above, which relate to the strategic management of the emerging HIV decline in Uganda in the mid-1990s, indicate that UNAIDS (then a newly formed institution) wanted to establish its multisectoral prevention approach and its wish to advocate for increased financial investment to mitigate the global impact of HIV/AIDS. Seemingly, the emerging signs of the Ugandan HIV decline were viewed with caution, as UNAIDS (in the mid-1990s) wanted to emphasise the growing problem of HIV/AIDS (rather than highlighting the emerging signs of Ugandan 'success'). Acknowledging 'success' in the fight against HIV/AIDS (especially within a sub-Saharan African country) potentially countered UNAIDS' desire to mobilise resources and to unify the broader UN system to fight HIV/AIDS via multisectoralism, which, at the time, was a new approach to HIV/AIDS prevention that departed from the older GPA prevention model (which was viewed as a limited and outmoded global HIV/AIDS prevention model).

## 6.7 Discussing the problem of Ugandan success and changes in the approach to global HIV/AIDS prevention

Findings have highlighted how institutional and political context adaptation appeared to influence the two competing behavioural change explanations in the mid-1990s. It can be stated that the closure of GPA in 1995, and the establishment of UNAIDS in 1996, catalysed a major policy shift in the approach to the prevention of HIV/AIDS at the global level. This

institutional transition, and the departure from GPA's biomedically focused HIV prevention strategies to UNAIDS' multisectoral HIV prevention approach, adapted the political context within which the debate over the competing behavioural change explanations amongst HIV/AIDS experts occurred. This adaptation consequently shaped the movement of the competing explanations within global HIV/AIDS policymaking networks, and possibly the agency of certain HIV/AIDS experts involved with analysis of Uganda behavioural evidence in the mid to late-1990s.

Data highlighted how the partnership reduction explanation seemingly failed to align with the prevailing institutional and political context, and the transition towards UNAIDS' newly developed multisectoral HIV/AIDS global prevention policy agenda. The partnership reduction explanation, and the subsequent decline in HIV prevalence, which was potentially catalysed by Ugandans communicating about the threat of HIV/AIDS, did not involve UNAIDS or its newly developed multisectoral HIV prevention approach. It was therefore potentially working against the evolving institutional and political climate and the shift towards UNAIDS' multisectoral HIV/AIDS prevention strategy, which aimed to promote the use of condoms (a tangible biomedical product that UNAIDS could advocate and raise funds for) to reduce the transmission of HIV at the global level. Importantly, UNAIDS was aiming to undertake two key tasks when it was formally established in 1996. First, to depart *from* the older GPA prevention model (which was viewed as being too biomedically focused and thus anachronistic) *towards* multisectoralism—an approach which aimed to unify multiple UN partners, state and non-state actors to fight HIV/AIDS through broad-based social and political mobilisation. Second, to support increased financial investment, via political advocacy, in order to implement HIV prevention policies that could be used to prevent the acquisition and transmission of HIV at the global level. Seemingly, the partnership reduction explanation held the potential to challenge these two key institutional goals of UNAIDS in the mid-1990s which is a surprising finding.

It is surprising as the partnership reduction explanation, which came about via oral communication within the Ugandan population, could have aligned with UNAIDS' multisectoral HIV prevention approach. This idea can be advanced as multiple sectors, state and non-state actors could have unified under the totem of multisectoralism to promote HIV/AIDS awareness campaigns (via broad-based social mobilisation) which highlighted the importance of domestic communication in fighting HIV/AIDS. However, data have illustrated that the partnership reduction explanation presented UNAIDS with potential funding dilemmas, as the signs of Ugandan 'success', emerged when UNAIDS was attempting to highlight the growing policy problem of HIV/AIDS at the global level (and UNAIDS' need to increase financial resources to support its newly developed multisectoral approach to address the global problem of HIV/AIDS).

The finding that the partnership reduction explanation may not have informed subsequent HIV/AIDS prevention policy output, raises a paradoxical notion namely the 'problem of Ugandan success'. Seemingly, the good news of Ugandan sexual behavioural change (that was potentially facilitated by Ugandan-initiated communication strategies) and its influence in leading to decreasing HIV seroprevalence rates, was not internalised by UNAIDS as this finding did not "filter through" (Low-Beer: 06/12/2011) the newly formed institution in the mid-1990s. Indeed, a broader process of "political filtering" (Low-Beer: 06/12/2011) appears to have influenced the partnership reduction explanation, and this political filtering arguably resulted in this explanation facing considerable difficulty in establishing itself as a credible explanation for the Ugandan HIV seroprevalence decline during the mid to late-1990s.

This difficulty can be mainly attributed to the partnership reduction explanation failing to align with the prevailing political and institutional environment, when UNAIDS was launched in 1996, and how this finding appeared to interfere with its multisectoral HIV/AIDS prevention strategy that was formally enshrined in UNAIDS' founding ECOSOC resolution in 1994. It has also been highlighted that the emerging signs of the Ugandan

HIV decline were possibly managed by UNAIDS, as the formative signs of HIV decline may have influenced one of UNAIDS' key functions—namely its institutional role to advocate for increased financial resources to mitigate HIV/AIDS at the global level from the mid to late-1990s onwards.

To recognise the formative Ugandan 'success' (when UNAIDS was only just beginning to establish itself as a new UN international organisation) may have resulted in the institution having to adapt (or at least question) its long-term development-centered response to HIV/AIDS at the global level. Importantly, UNAIDS was formed to advocate for greater financial mobilisation to mitigate HIV/AIDS via multisectoralism—which was a long-term development centered prevention approach (which thus required extensive external financial support to implement over a long-term timeframe). By acknowledging the partnership reduction explanation, while the institution was attempting to establish itself as a competent international organisation that could implement a better HIV/AIDS prevention model than GPA, would have called into question UNAIDS' need to keep emphasising the growing problem of HIV/AIDS and its institutional desire to raise more financial support to fight HIV/AIDS globally. Stated plainly, UNAIDS had to maintain the narrative of the ongoing problem of HIV/AIDS in the mid to late-1990s, rather than acknowledging (and acting upon) the emerging signs of 'success' within Uganda via partnership reduction underpinned by oral communication. Acknowledging an effective Ugandan-based HIV prevention model (oral communication and subsequent partnership reduction) could have conceivably resulted in UNAIDS having to adapt elements of its multisectoral HIV prevention policy agenda, and the institutions desire to advocate for increased funding to support the production and dissemination of condoms at the global level.

Findings also highlighted that the competing behavioural change explanations, and the significance afforded to the explanations, were influenced by decision-makers' institutional position within UNAIDS, the importance of working with the prevailing institutional and policy environment and notions of institutional loyalty. Perhaps unsurprisingly,

those HIV/AIDS experts who possessed a more senior institutional position (like Michel Caraël) had the power to control the analysis, and dissemination of, the Ugandan sexual behavioural change evidence (which were used to support the development of SGS and formative explanations for Uganda's HIV decline). Less senior decision-makers, or HIV/AIDS experts who did not endure the GPA/UNAIDS transition, naturally were at a power-based disadvantage in terms of being able to advance their behavioural change explanations within the broader UN system. This arguably resulted in other avenues being used to publish competing explanations that could account for the Ugandan HIV decline (i.e. Rand Stoneburner's and Daniel Low-Beer's 2004 article in the journal *Science*). The importance of working with, rather than against, the strategic direction of senior management within UNAIDS was also outlined. Naturally, failure to align oneself with the prevailing HIV prevention policy agenda within UNAIDS (i.e. multisectoralism) seemingly had consequences for one's institutional 'survival' in the mid-1990s.

An interesting finding that emerged during data collection was the notion of institutional loyalty. Data highlighted that decision-makers, who functioned in an institutionally loyal manner were able to endure the GPA/UNAIDS transition and therefore able to promote their respective behavioural change explanations that could account for the Ugandan HIV decline. Functioning loyally to UNAIDS' multisectoral approach, and senior level management within UNAIDS, arguably facilitated more politically savvy HIV/AIDS experts to facilitate their respective explanations of Ugandan behavioural evidence ahead of other competing explanations. This notion again highlights the importance of broader institutional and political change upon the competing behavioural change explanations, and the requirement for evidence to be strategically adapted to suit the prevailing political climate in order to inform subsequent policy output. The manner in which Peter Piot, the former Executive Director of UNAIDS, internalised the competing Ugandan behavioural change explanation was also acknowledged as a key factor in potentially determining the movement of evidence within UNAIDS from 1996 onwards.

Ostensibly, Peter Piot, the former Executive Director of UNAIDS, considered the explanation of behavioural change, advanced by Michel Caraël, the former head of HIV prevention within UNAIDS, to be more convincing than the competing explanation advanced by Rand Stoneburner a former GPA/UNAIDS epidemiologist. Two reasons can explain Peter Piot's possible alignment to Michel Caraël's increased condom uptake explanation. First, the perception of Michel Caraël's expertise within a relatively compact epistemic community (Haas: 1992: pp. 1) and his construction as a 'guru' of socio-behavioural data analysis. Second, the notion that the condom uptake explanation potentially aligned more directly with Peter Piot's multisectoral approach to global HIV/AIDS prevention (as condoms were a tangible biomedical product that UNAIDS could advocate for and subsequently distribute via the multisectoral approach at the global level). Notions of policy entrepreneurship are again key to the apparent dominance of Caraël's condom uptake explanation over Stoneburner's partnership reduction explanation. Via a strategic alignment to the prevailing institutional and political climate (and the possible strategic misinterpretation of Uganda sexual behavioural change evidence itself) Caraël was potentially able to mould the behavioural change evidence, emerging from Uganda, in a manner that would work with UNAIDS' enhanced global HIV prevention policy agenda namely multisectoralism.

## 6.8 Chapter summary

This chapter emphasised that institutional and political adaptation, namely, the shift from GPA to UNAIDS in the mid-1990s and the initiation of a new global HIV prevention approach (multisectoralism) appeared to influence the behavioural change explanations advanced by competing HIV/AIDS experts. Owing to the apparent failure of the partnership reduction explanation to align with the evolving institutional and political context, and the implications of the partnership reduction explanation in challenging elements of UNAIDS' multisectoral HIV prevention policy agenda, it did not appear to inform subsequent HIV/AIDS policy output in the mid to late-1990s. Data have suggested that the partnership reduction explanation was



ostensibly politically filtered by UNAIDS in the mid-1990s. This arguably occurred as the partnership reduction explanation, had it been widely disseminated in the mid-1990s, would have called into question UNAIDS' predesigned HIV prevention policy agenda, and the need for UNAIDS to advocate for increased financial resources to mitigate HIV/AIDS via the uptake of condoms that could be distributed through the multisectoral response at the global level. Seemingly, it was more important for UNAIDS (then a newly developed UN institution that aimed to depart from an outdated HIV prevention model used by its institutional predecessor GPA) to frame itself as a credible international organisation that could mitigate HIV/AIDS at the global level. Key to its perception of credibility was the introduction of an 'enhanced' multisectoral HIV prevention policy agenda, and its need to advocate for increased financial mobilisation to fight HIV/AIDS at the global level. Data appear to suggest that the emerging signs of the Uganda 'success' story were viewed by UNAIDS with trepidation. Indeed, the formative signs of 'success' (and certain forms of evidence which could account for the HIV decline in Uganda) were perhaps downplayed (and potentially strategically misinterpreted) by UNAIDS as it had to promote the narrative of HIV/AIDS as a growing global health policy problem (that needed to be fixed via multisectoralism). Acknowledging a successful Ugandan-based HIV prevention model (underpinned by oral communication and subsequent partnership reduction) could have conceivably resulted in UNAIDS having to question elements of its multisectoral prevention agenda and its need to magnify the growing problem of HIV/AIDS at the global level for financial reasons. In the interest of good academic practice, please note that individual participants were given the right to reply to the highly personalised claims outlined within this chapter, however no responses were received by the researcher.

## **CHAPTER SEVEN: Discussion**

### **7.1 Introduction to chapter**

Via an analysis of SGS, this thesis sought to examine contested explanations for the decline in HIV prevalence in Uganda and the role of evidence in the development of global HIV prevention policy in the 1990s. This chapter critically reflects on the findings reported in the preceding three chapters, examining their contribution to existing empirical literature on the development of SGS and prevailing explanations for the Ugandan HIV prevalence decline of the 1990s. Reflections on the implications for our understanding of the relationship between evidence and policy within global and Ugandan policymaking contexts are also advanced. More precisely, this chapter aims to discuss the study's empirical contributions to existing accounts of SGS's development, to build upon historical narratives of Uganda's HIV 'success' story, and to engage with existing theoretical frameworks that have attempted to model the relationship between evidence and policy, in particular Stevens' (2007) evolutionary model—considering its applicability pertaining to LIC contexts. The main findings of the study are summarised, its limitations and strengths are discussed and directions for future research are suggested.

### **7.2 Summary of the main findings**

Research findings coincide significantly with official accounts locating the development of SGS at a UNAIDS sponsored HIV/AIDS surveillance improvement workshop held in Nairobi, Kenya, in February 1997, but offer a more complex picture of how and why this development came about. Official accounts from both UNAIDS and the WHO present the development of SGS as a technocratic, problem-solving response to limitations in established global HIV/AIDS surveillance approaches. UNAIDS/WHO

documents highlight the significance of Ugandan sexual behavioural change evidence for the development and introduction of SGS (UNAIDS: 1998a; UNAIDS/WHO: 2000). Although findings from this research confirm UNAIDS' and the WHO's professed need for improved HIV/AIDS surveillance systems, they suggest a more complex picture in terms of the extent to which SGS was evidence-based and highlight contested interpretations of this evidence among HIV/AIDS experts.

The introduction of SGS by UNAIDS/WHO may be understood as serving both technical and broader strategic purposes in the late-1990s and early 2000s. As specified in UNAIDS/WHO policy documentation (UNAIDS: 1998a; UNAIDS/WHO: 2000), SGS sought to improve older global HIV/AIDS surveillance methodologies via the integration, and triangulation of, multiple data sources—in particular behavioural surveillance data sources. However, the introduction of SGS also appears to have served two broader purposes, functioning as something akin to a marketing tool to help promote the institutional identity of UNAIDS, while concurrently signalling a shift towards a multisectoral approach that aimed to unify epidemiological and social scientific disciplinary approaches in the mid to late-1990s onwards.

While interviewees' accounts coincide in describing a decline in Ugandan HIV prevalence during the 1990s, based upon the analysis of Ugandan sexual behavioural change data sources, they present divergent interpretations of this evidence which became significant in the development of SGS and the development of subsequent global HIV prevention policy. One interpretation focused on a reduction in multiple partnerships within the Ugandan population as the key change driving the decline in HIV prevalence, while a contrasting explanation focused on increased use of condoms as the primary cause of this decline. Interviewees' accounts suggest a process of competition, whereby different actors sought to secure the primacy of their preferred interpretation in institutional understandings of Uganda's HIV prevalence decline and in the development of SGS. Certain interviewees assert that disciplinary bias and institutional marginalisation have

contributed to the subordination of explanations focused on a decline in multiple sexual partners, while the policy entrepreneurship of Michel Caraël, the former head of HIV prevention within UNAIDS, appears influential in explaining the ascendancy of explanations focused on increased condom use. Despite these contestations around the evidence used to inform the development of SGS and approaches to HIV prevention in the 1990s, UNAIDS documents and peer-reviewed publications from this period highlight one interpretation (that of increased condom uptake) which has emerged as the official explanation for the success of HIV control in Uganda. The transition from GPA to UNAIDS, and the initiation of a multisectoral HIV prevention approach, appear as important contextual and institutional influences in the interpretation of behavioural change evidence for Uganda's HIV decline. The inability of the partnership reduction explanation to align with the evolving institutional and political orthodoxy, and the potential for this explanation to challenge UNAIDS' new focus on multisectoral HIV prevention, may help to explain why it did not inform subsequent HIV/AIDS policy and does not appear in official accounts of SGS's development. In contrast, explanations focused on increased condom use were consistent with UNAIDS' HIV prevention policy agenda (including its emphasis on multisectoral approaches) and appeared to reinforce the organisation's need for increased financial resources to mitigate HIV/AIDS via the distribution and promotion of condoms.

### 7.3 Contributions of study

This study makes empirical and analytical contributions to knowledge in three areas. First, it provides new understandings of SGS's policy development, while introducing previously unidentified reasons contributing towards its formal introduction by UNAIDS/WHO in 2000. Second, it provides fresh insights into the Ugandan HIV prevalence decline (otherwise known as the Ugandan HIV/AIDS 'success story') that emerged during the 1990s. Third, it has located and examined an array of broad factors that can influence the relationship between evidence and policy

pertaining to sub-Saharan African and global level policymaking contexts—factors which query the notion, and practice of, EBPM in both contexts.

### *7.3.1 Contributions to existing accounts explaining the development of SGS as advanced by UNAIDS/WHO*

This study presents findings which challenge elements of existing accounts of SGS's development as advanced by UNAIDS/WHO (UNAIDS: 1998a; UNAIDS/WHO: 2000). These official accounts provide a somewhat simplistic picture of how evidence was used to support the introduction of SGS, and do not explicitly acknowledge some of the reasons that appear to have contributed to its formal initiation in 2000. As noted in section 4.1 of the first results chapter, UNAIDS (1998a) depict the policy development of SGS as a problem-solving adaption to older, serologically focused, HIV/AIDS surveillance approaches supported by Ugandan sexual behavioural change evidence. Indeed, it is claimed that older HIV surveillance approaches could be built upon in reaction to the emergence of new knowledge – namely Ugandan behavioural surveillance data – which could be used to interpret trends in serosurveillance—thus validating the SGS approach (UNAIDS: 1998a: pp. 5).

While this account reflects the significance of the Nairobi workshop in contributing to the development of SGS - which interview data confirms - it should be understood as somewhat simplistic in its portrayal of how Ugandan evidence was used to improve older global HIV/AIDS surveillance approaches, and the functions that SGS actually performed. While evidence was certainly used to inform the development of SGS – particularly Ugandan sexual behavioural change evidence – the findings of this study challenge the above narrative depicting SGS as strictly 'evidence-based'—including the inference that the introduction was used in a purely rational or problem-solving manner. Significantly, HIV/AIDS experts involved with SGS's development differed in their interpretation of the available evidence, resulting in a form of competition between contrasting explanations for

Uganda's decline in HIV prevalence. Explanations emphasising a reduction in multiple sexual partners appear to have been subject to a degree of institutional marginalisation within evolving institutional and political contexts. Thus, aligning with the work of Hunsmann (2012), this case illustrates how political obstacles have influenced the use of evidence within the field of global HIV policy (Hunsmann: 2012: pp. 1477). It is also clear that Ugandan evidence, used to support the development of SGS and formative explanations of Uganda's HIV decline, has been interpreted and used somewhat selectively which, congruent with Weiss (1979), suggests a political – rather than a neutrally 'rational' - use of evidence within Ugandan and global level policymaking contexts.

Three particular facets of existing UNAIDS/WHO accounts describing the development of SGS – and the role of evidence in this process - can be queried on the basis of findings generated within this study. First, the depiction of SGS's policy development being based on a unified and undisputed Ugandan evidence-base. Second, assertions made within UNAIDS policy documentation which claim the successful partnership between epidemiologists and social scientists in the mid to late-1990s (UNAIDS: 1998a: pp. 5). Third, findings from this research suggest there were additional reasons which underpinned the formal development of SGS (in addition to the technical, problem-solving role described in official accounts).

Analysis identified a somewhat broader array of evidence that indirectly contributed to the policy development of SGS (alongside the 1989 and 1995 population-based surveys of sexual behavioural change and the 300 small-scale sociological surveys mentioned in official accounts). As noted in section 4.4 of the first results chapter, older HIV/AIDS surveillance data from the WHO's GPA, sexual behavioural evidence from DHS surveys, and data emerging from the HIV/AIDS epidemic in the United States in the 1980s all informed the conceptual development of SGS. However, these sources of evidence were not mentioned in official UNAIDS/WHO accounts of SGS's development. Existing UNAIDS/WHO documents present a somewhat

rudimentary account of the evidence which helped support SGS's introduction, emphasising (in line with interview data) the principal role of Ugandan sexual behavioural change evidence. However, multiple, and at times contradictory narratives pertaining to the function of Ugandan evidence, and its role in supporting the development of SGS, were generated by certain interviewees—which again calls into question the simplistic and largely technocratic depiction of SGS's evidence-base as advanced by UNAIDS in the late-1990s.

The official accounts of SGS's development, and the portrayal of a single, undisputed Ugandan evidence-base, serve as a reminder that documents produced by institutions like UNAIDS/WHO should not be viewed as neutral sources of information, as they are often written for particular audiences and specific purposes (Yin: 2003: pp. 86 – 87). It was arguably important for UNAIDS to portray SGS as a problem-solving, evidence-based policy within official accounts of its development in order to demonstrate UNAIDS' commitment to evidence-based approaches—a commitment which maybe viewed as somewhat rhetorical in light of the findings reported within this study.

It can also be reported that UNAIDS' policy documentation was used strategically to promote its institutional standing in order to create a narrative of technical efficiency in relation to global HIV/AIDS surveillance and global HIV prevention. Via the presentation of SGS as a rational policy development in the late-1990s, and the advancement of an outwardly homogenous Ugandan evidence-base, UNAIDS/WHO documentation successfully framed the development of SGS as both unproblematic and evidence-based. However, findings call into question the extent to which such descriptions, as advanced by UNAIDS/WHO, are fully comprehensive or indeed persuasive.

An additional claim, asserted within official UNAIDS/WHO policy documentation, can also be questioned in light of the findings generated within the study. It was recognised by UNAIDS (1998a) that barriers

between the medical community and social scientists existed during the time period that SGS emerged, and that “those barriers are hard to break down” (UNAIDS: 1998a: pp. 5). The Nairobi workshop – the focusing event where SGS emerged – was perceived as “help[ing] to build up effective partnerships between behavioural scientists and epidemiologists” (UNAIDS: 1998a: pp. 12). The depiction that “effective partnerships” (UNAIDS: 1998a: pp. 5) between HIV/AIDS experts – from contrasting disciplinary backgrounds – were formed during the Nairobi workshop is not entirely convincing given findings from interviews.

In contrast, findings from the project suggest a high degree of contestation between competing HIV/AIDS experts from contrasting epidemiological and social-scientific backgrounds in the mid to late-1990s. As noted by Schoepf (2004), action within the discipline of public health takes places on a terrain of contested meaning and unequal power where different kinds of knowledge struggle for control (Schoepf: 2004: pp. 41). Rather than effective partnerships being formed, at the time of the development of SGS, experts from different disciplinary backgrounds vied over evidence where different forms of knowledge, congruent with Schoepf (2004), struggled to gain competitive advantage in the development of subsequent HIV/AIDS policy output (and formative explanations for Uganda’s HIV decline). The portrayal of effective partnerships being formed between HIV/AIDS experts within UNAIDS policy documentation conceals how experts, involved with the development of SGS and formative accounts of Uganda’s HIV decline, competed to secure the primacy of their opposing interpretations of evidence, and how disciplinary barriers arguably remained in place and contributed to shaping the development of SGS.

Findings have also suggested that SGS was introduced by UNAIDS/WHO for a range of previously unidentified reasons. In addition to the need for SGS to improve older global HIV/AIDS surveillance approaches, findings show that SGS functioned as a rebranding tool to promote the institutional credibility of UNAIDS and to signal the unity of social scientific and epidemiological approaches in the mid to late-1990s. Pertaining to SGS



functioning as a rebranding tool, findings illustrate that SGS helped UNAIDS to re-launch global HIV surveillance methodological approaches, with the new packaging of SGS serving to promote the policy within international organisations involved with global HIV/AIDS prevention in the late-1990s. Findings also indicate that SGS acted as a marketing device which could facilitate the outward construction of UNAIDS as a credible, and efficient, institution that could address the global policy problem of HIV/AIDS in a successful manner. These findings have direct parallels with the notion of policy branding relating to DOTS for the treatment and wider control of tuberculosis at the global level. In this context, Ogden et al (2003) demonstrated that after a prolonged period of neglect, financial resources were mobilised in order to promote tuberculosis control on the national and global public health policy agenda (Ogden et al: 2003: pp. 179).

It is argued by Ogden et al (2003), that via the marketing of the improved tuberculosis control policy with the DOTS brand, the policy successfully generated attention towards the problem of tuberculosis, which, in turn, facilitated the transfer of the newly branded policy to LMICs across the globe. In reaction to the findings that emerged from this thesis, it can be stated that SGS was marketed, or branded by UNAIDS, to promote a perception of institutional credibility, whilst concurrently positioning HIV/AIDS surveillance back on the public health agenda at the national and global levels.

Analyses also suggest that SGS served a symbolic purpose in signalling the apparent unification of two formerly distinct disciplines (socio-behavioural and epidemiological) within UNAIDS/WHO in the late-1990s. Older global HIV/AIDS surveillance approaches had formerly analysed epidemiological and socio-behavioural HIV data sources in isolation—especially within the WHO's GPA (Barnett & Whiteside: 2002: pp. 23). There was, therefore a commitment to transdisciplinary research by UNAIDS to unify the two fields, and experts from both disciplines alike, in the late-1990s.

However, the process of successfully bridging these disciplinary fields was constructed as unproblematic by certain interviewees, whereas others asserted that the process was more difficult, acknowledging that there was a degree of resistance to merge socio-behavioural data approaches with epidemiological approaches in the early to mid-1990s. As noted above, it was claimed by UNAIDS (1998a) that effective partnerships were created during the Nairobi workshop, with the implication that established barriers between epidemiologists and social scientists started to breakdown during the focusing event where SGS emerged. However, the degree of contestation and competition that actually occurred between HIV/AIDS experts involved with the development of SGS, calls into question the functional ability of SGS to help unify competing HIV/AIDS experts from separate disciplinary backgrounds. The findings again serve as a reminder that documentary sources of evidence should be viewed critically and are constructed by their authors in an attempt to consolidate a variety of views and opinions (Weishaar: 2013: pp. 258). Existing UNAIDS/WHO accounts of SGS's development are thus somewhat one-dimensional as they mask how a range of evidentiary sources informed its policy development, how experts competed over Ugandan evidence and the role that contestation, rather than partnership, played during its formal introduction.

### *7.3.2 Contributions to existing accounts of Uganda's HIV 'success' story*

Findings from this study have generated fresh insights into existing accounts of Uganda's HIV 'success' story, as constructed by HIV/AIDS experts from international organisations and the Ugandan Government, in the early to mid-1990s. Via the analysis of SGS it emerged that Ugandan sexual behavioural change evidence, namely two population-based surveys conducted in 1989 and 1995 combined with 300 small-scale sociological surveys, were used by HIV/AIDS experts to generate explanations for Uganda's HIV decline. However, results demonstrate that certain HIV/AIDS experts, involved with the analysis of these sources of evidence, competed to generate support for explanations highlighting the role of either increased

condom uptake, or a reduction in multiple sexual partners, as the main reason behind declining HIV prevalence in Uganda. Significantly, accounts of this contestation among HIV/AIDS experts provide new insights which challenge official explanations for the HIV decline as portrayed by UNAIDS in the mid to late-1990s.

A key strength of this thesis is the data it presents reflects access to HIV/AIDS experts from Ugandan and Genevan contexts—experts who were directly involved with constructing formative explanations of Uganda’s HIV decline in the early to mid-1990s. Interview data obtained from these key HIV/AIDS experts, who were among the first to analyse the original data sources highlighting the emerging HIV decline in Uganda, enabled the identification of a range of broader factors – which appear to have influenced the development and depiction of the Ugandan HIV decline. Analysis of interview data suggests that claims of disciplinary bias, the influence of policy entrepreneurship and data marginalisation affected the competing increased condom uptake and multiple partnership reduction explanations that could account for the Ugandan HIV decline. These factors, which appear to be central elements of the broader competition that occurred among HIV/AIDS experts, seem to have directly contributed towards the possible subordination of an explanation focused on a reduction in multiple partners and the ascendancy of an increased condom uptake explanation.

The identification of these broader influences thus suggests that existing narratives of Uganda’s HIV decline, and literature which has attempted to explain the Ugandan HIV ‘success’ story itself, can be updated and expanded on the basis of the empirical findings generated within this study. As noted in earlier chapters, Uganda has been constructed as the first HIV/AIDS success story or ‘poster child’ within sub-Saharan Africa (Kiweewa: 2008: pp. 54). Logically, as the first country in sub-Saharan Africa to experience decreasing HIV trends, the causal reasons contributing to this decline have been of analytical interest to international organisations and researchers within the field of HIV/AIDS prevention for the past 25 years. Indeed, there is an extensive body of literature that has attempted to reveal the reasons

that contributed towards the Ugandan HIV decline, with an array of contrasting explanations having been advanced to account for what actually caused the declining trends in HIV infection (Parkhurst: 2001; Parkhurst: 2002; Parkhurst: 2012; Okuonzi & Epstein: 2005; Genius & Genius: 2005; Blum: 2004; Tumushabe: 2006; Green et al: 2006; Slutkin et al: 2006; Merson: 2006; Hogle: 2002; Stoneburner & Low-Beer: 2004a; 2004b; Kirby: 2008; Kiweewa: 2008; UNAIDS: 1998a; UNAIDS: 1998b; Asiimwe-Okiror et al: 1997).

One of the central explanations, advanced for Uganda's declining HIV prevalence, focuses on the impact of Uganda's ABC strategy (Singh et al: 2003; Slutkin et al: 2006; Blum: 2004; Murphy et al: 2006). Indeed, one of the most contested elements of existing explanations for the Ugandan HIV 'success' story concerns the significance of the individual elements of the ABC explanation, with various individuals, organisations and national governments highlighting the discrete 'A' (abstinence), 'B' (being faithful/avoidance of multiple sexual partners) and 'C' (condom) elements (Green et al: 2006: pp. 335).

As noted within section 5.2.1 of the second results chapter, certain participants aligned themselves - either fully or partially - to an increased condom uptake or a reduction in multiple partnership explanation as the key reason that led to declining trends in HIV infection within the country. A range of processes and strategies contributed to the subsequent dominance of the increased condom uptake explanation, and the apparent subordination of explanations emphasising a reduction in multiple partnerships. These processes maybe categorised into three broad groups—that is: the influence of disciplinary bias, policy entrepreneurship and claims of data marginalisation. These three factors, and their influence upon existing accounts of the Ugandan HIV 'success' story will now be discussed.

Importantly, findings demonstrate that certain HIV / AIDS experts, who were among the first to create formative explanations of the emerging Ugandan HIV decline, competed over two different interpretations of the data,

highlighting different possible changes in sexual behaviour which could account for sub-Saharan Africa's first HIV 'success'. Interpretations focusing on multiple partnerships, advanced by epidemiologists Rand Stoneburner and Daniel Low-Beer, did not appear to gain traction as a valid explanation for the decreasing HIV prevalence within Uganda in the mid to late-1990s. In contrast, interpretations focused on increased condom uptake, advanced by Michel Caraël a social scientist, and former head of HIV prevention within UNAIDS, appeared to succeed in establishing itself as a valid explanation for decreasing HIV trends. Multiple factors appear to have contributed to the manner in which the condom-based explanation came to dominate the competing partnership reduction explanation, including claims of disciplinary bias, the influence of policy entrepreneurship and data misinterpretation. In combination, these factors apparently shaped the relationship between evidence and policy within global policymaking networks and formative narratives of the Ugandan HIV 'success' story itself.

Results from this research suggest that discrediting tactics, including references to relevant expertise and disciplinary bias, inhibited certain constructions of Ugandan behavioural evidence from informing subsequent policy output. Indeed, results highlight that Rand Stoneburner's expertise, in relation to socio-behavioural data analysis, was challenged by Michel Caraël, the former head of HIV prevention within UNAIDS. The purported tactical construction of Rand Stoneburner as being poorly equipped to analyse Ugandan sexual behavioural change evidence – principally on the grounds of being an epidemiologist – can be understood as an effective discrediting technique intended to undermine support for the partnership reduction explanation. This discrediting strategy has arguably been an important and overlooked element of the broader competition between HIV/AIDS experts, who attempted to frame their respective sexual behavioural change explanations as preeminent in the mid to late-1990s.

The influence of policy entrepreneurship also emerged as a key factor which enabled an increased condom uptake explanation to dominate the rival reduction in multiple partnership explanation. Congruent with notions

advanced by Daniels & Lewin (2008) and Burris et al (2011), the role of policy entrepreneurship was seemingly key in influencing how certain forms of evidence were perceived as more credible than others, and how particular interpretations of evidence were subsequently able to inform HIV/AIDS policy output ahead of others. Aligning with Burris et al (2011), who acknowledge the importance of a well-placed policy entrepreneur for synthesising operational research findings into policy, in relation to HIV/HSV-2 interactions within Ghana, findings illustrated that Michel Caraël, the former head of HIV prevention within UNAIDS, functioned as a policy entrepreneur. This potentially enabled the increased condom uptake explanation to inform subsequent HIV/AIDS policy output (more successfully than competing HIV/AIDS experts who attempted to promote a partnership reduction explanation).

Caraël's ability to promote the increased condom uptake explanation within globalised HIV policymaking contexts, reflects his senior institutional positions which aligns with findings advanced by Hutchinson et al (2011). Usefully, Hutchinson et al (2011) note that the position of policy entrepreneurs, within distinct institutional contexts, is an important factor in facilitating the movement of evidence and the development of subsequent policy output. According to their analysis, policy entrepreneurs who possessed senior institutional positions were able to control the interpretation of evidence and thus influence subsequent policy development within the contexts of Malawi, Uganda and Zambia.

Michel Caraël similarly possessed a senior-level institutional position within UNAIDS, which was arguably significant in enabling the increased condom uptake explanation to inform subsequent HIV/AIDS policy output—ahead of the partnership reduction explanation principally advanced by an HIV expert who was constructed as being poorly equipped to analyse behavioural data due to his epidemiological background. As head of HIV prevention within UNAIDS and chair of the 1997 Nairobi workshop (where SGS emerged and the formative explanations for Uganda's HIV decline were discussed), Caraël possessed the requisite institutional power to promote the

condom uptake explanation more effectively than the competing partnership reduction explanation.

Perhaps more importantly, Michel Caraël also demonstrated one of the key attributes of a policy entrepreneur within HIV/AIDS policymaking networks, namely, their possession of a known level of expertise which, in turn, confers an entitlement to be heard within distinct policy environments (Kingdon: 1995: pp. 180 – 181). Indeed, findings illustrated that Caraël's perceived socio-behavioural expertise, particularly within UNAIDS, enabled the diffusion of his preferred explanation of sexual behavioural change (taking place within Uganda in the early to mid-1990s). The significance afforded to Michel Caraël's expertise in relation to the acceptance of competing evidence explanations, emerges from the interview data as being key in determining the acceptance, or non-acceptance, of the two behavioural change explanations. Findings illustrate that Caraël's construction of socio-behavioural expertise positioned him as *the* central authority (within a relatively compact policymaking network) pertaining to socio-behavioural data analysis. This view was corroborated by HIV/AIDS experts from both Genevan and Ugandan contexts during data collection.

Indeed, Caraël was constructed as a “guru” (former UNAIDS official: 19/9/2011) of socio-behavioural data analysis and the perception of his expertise by others, including the former Executive Director of UNAIDS, arguably facilitated the dominance of his explanation of Ugandan sexual behavioural change. Interlinked with the social construction of Caraël's expertise, is his close and productive relationship with Peter Piot, the former Executive Director of UNAIDS—which illustrates an additional facet of policy entrepreneurship as advanced by Kingdon (1995). Kingdon maintains that policy entrepreneurs have well-developed political connections and effective negotiation skills—underpinned by their savvy and tenacious nature (Kingdon: 1995: pp. 181). On the basis of the research findings, it can be posited that Caraël's close, and institutionally productive relationship with other decision-makers within UNAIDS, especially Peter Piot, facilitated his ability to negotiate his explanation of sexual behavioural change to gain

wider political acceptance within UNAIDS than other competing sexual behavioural change explanations.

Usefully, Burris et al (2011) also discovered that a key mechanism which facilitated policy entrepreneurs' use of evidence (and the initiation of subsequent policy change) was personal ties, including either old friends and colleagues, in distinct institutional environments. Given his political connections, his perceived status as a socio-behavioural expert, his senior-level institutional position and his personal ties with other powerful decision-makers, it can be understood why Michel Caraël was able to shape the interpretations, and use of, Ugandan behavioural evidence in order to promote his preferred framing of the policy problem of HIV/AIDS in Uganda and how to address this problem in multiple policy fora. Kingdon (1995) reasons that the primary motivation for policy entrepreneurs to function in an active manner within the broader policymaking process is the promotion of personal self-interest via the protection of one's bureaucratic turf, the expansion of one's individual agency and thus the advancement of one's career (Kingdon: 1995: pp. 123). Findings within this study can suggest an additional motivation for policy entrepreneurs to function in an active manner within the broader policymaking process (at least within the context of global level HIV/AIDS policymaking networks). Namely, their wish to advance, and defend, their own ideas and to increase their own epistemic dominance, which, in turn, facilitates them to maintain their competitive advantage over less powerful experts in adversarial policymaking environments.

Claims of data misinterpretation were also advanced by participants during interviews. Four participants made claims concerning the misinterpretation of the reduction in multiple partnership explanation. A version of this data purported misinterpretation is presented within Asimwe-Okiror et al (1997) and 'A Measure of Success in Uganda' (UNAIDS: 1998b). The claims of data misinterpretation have implications for existing narratives of the Ugandan HIV decline and our understanding of the relationship between evidence and policy within Ugandan and global level policymaking contexts. In the



absence of this purported misinterpretation, it can be hypothesised that the reduction in multiple partnership explanation might have informed explanations for Uganda's HIV decline and the subsequent development of HIV/AIDS prevention policy output from 1996 onwards. However, findings within this study appear to indicate that the multiple partnership reduction explanation was not formally published until 2004 in the journal *Science* (8 years after evidence of this behavioural change emerged from the analysis of the Ugandan population-based surveys conducted in 1989 and 1995).

The discovery that some sources of evidence were purportedly misinterpreted in the account of Uganda's HIV decline and the development of SGS is perhaps unsurprising. The emerging signs of the 'success' of HIV control from a sub-Saharan African country for the first time in the history of the global HIV/AIDS pandemic had significant implications. Dickinson & Buse (2008) note that politics, ignorance and ideology can have a greater influence on HIV policy development than do evidence and best practice—and this has been presented as particularly applicable within LMICs (Dickinson & Buse: 2008: pp. 1). It is additionally noted by Hunsmann (2012), that the development of HIV prevention policy, within the context of Tanzania, is far from being evidence-driven, noting that HIV policy is the result of a politically negotiated aggregation of competing, and frequently non-optimising rationalities, among policymakers who have different ideas about the prevention of HIV (Hunsmann: 2012: pp. 1477). The acknowledged political determinants of HIV/AIDS policy development, and the political implications of the explanations that could account for the Ugandan 'success' story, are likely to have been key factors in the use of evidence for broader political purposes within Ugandan and global level contexts in the mid to late-1990s. Okware et al (2005) note that debate over the Ugandan HIV decline has often revolved around conviction or ideology rather than evidence (Okware et al: 2005: pp. 627). Findings within this study congruent with Okware et al (2005) indicate that certain HIV/AIDS experts, involved with the construction of explanations for Uganda's HIV decline, were seen by some actors with competing perspectives as being perhaps driven

primarily by conviction (and broader political concerns) in their preferred explanation for the Ugandan HIV 'success' story.

The political use of evidence, as opposed to a purely technocratic use, is again unsurprising—especially within the field of public health. As noted by Cookson (2005), experts within the field of public health tend to make a highly selective use of evidence, often reflecting political incentives, psychological biases and an over-confidence in one's own judgement (Cookson: 2005: pp. 119). It is also acknowledged by Banta (2003), that representations of evidence can be biased, willingly or unintentionally, or even fabricated, and that evidence utilisation is based upon a combination of professional judgement and common sense, with the emergence of convincing evidence, in public health, frequently being a matter of presentation and rhetoric (Banta: 2003: pp. 569). Findings in this study are congruent with these notions, with certain HIV/AIDS experts using evidence in an apparently strategic or political manner. This links with Weiss' (1977) perceptive summation of policymaking itself as an inherently political process, with the basic aim of reconciling interests in order to negotiate a consensus, rather than implementing logic and truth (Weiss: 1977: pp. 533).

Congruent with Young (2005) and Bowen & Zwi (2005), the relationship between evidence and policy - in the case of SGS - has been influenced by political processes and evolving political contexts (Bowen & Zwi: 2005: pp. 601). The period during which the 1989 and 1995 population-based surveys were being analysed by HIV/AIDS experts coincided with a major institutional transition in global HIV/AIDS governance, and the initiation of a novel, multisectoral HIV/AIDS prevention approach. These contextual developments were influential in shaping the presentation of competing explanations for Uganda's HIV decline, and possibly the agency of HIV/AIDS experts involved within the analysis of Ugandan behavioural evidence in the mid to late-1990s.

Analysis suggests that the closure of the WHO's GPA in 1995, and the establishment of UNAIDS in 1996 catalysed a major policy change in the

approach to global HIV/AIDS prevention—and more broadly global HIV/AIDS governance. This institutional transition and the departure from GPA's biomedically focused HIV prevention model to UNAIDS' multisectoral HIV prevention approach, transformed the political context within which the debate over the competing behavioural change explanations among HIV/AIDS experts occurred. Analysis highlighted that this institutional adaptation had a direct influence upon the increased condom uptake and the partnership reduction explanation that could account for declining HIV trends in Uganda.

The partnership reduction explanation and the successive decline in HIV prevalence which was potentially catalysed by Ugandans communicating about the threat of HIV/AIDS, did not involve UNAIDS or its newly developed multisectoral HIV prevention approach. Therefore, it was possibly working against the evolving institutional and political environment and the movement towards UNAIDS' multisectoral HIV/AIDS prevention strategy, which aimed to promote the use of condoms (a tangible biomedical product that UNAIDS could advocate and generate funds for) to reduce the global transmission of HIV. It could be advanced, aligning with Majone (1989), that the policy idea of an HIV prevention model, primarily based upon partnership reduction, was not adopted by UNAIDS as it was arguably not communicated persuasively, nor indeed did it meet the demands of the wider political environment (Majone: 1989: pp. 165). However, the discovery that the partnership reduction explanation, which was catalysed via oral communication, and broader social mobilisation within the Ugandan population, did not inform HIV/AIDS prevention policy within UNAIDS is somewhat surprising. Arguably, the partnership reduction explanation could have aligned with UNAIDS' multisectoral HIV prevention approach as a myriad of sectors, state and non-state actors could have unified under the banner of multisectoralism to promote HIV/AIDS awareness campaigns – via broad-based social mobilisation – which highlighted the importance of domestic communication in combatting HIV/AIDS.

However, analysis suggests that the partnership reduction explanation presented UNAIDS with a possible predicament, as the signs of Ugandan 'success', emerged when UNAIDS was attempting to highlight the growing problem of HIV/AIDS at the global level (and its institutional need to advocate for increased financial resources to support its newly developed multisectoral approach to address the global problem of HIV/AIDS). It can be advanced that certain HIV/AIDS experts within UNAIDS, who were perceptive to the prevailing institutional and political environment (i.e. policy entrepreneurs like Michel Caraël) actively stressed the principal significance of increased condom uptake as an explanation for declining HIV trends in Uganda. Via the promotion of increased condom uptake, based upon the analysis of the 1989 and 1995 population-based surveys, UNAIDS could subsequently advocate for increased condom distribution as an 'evidence-based' HIV prevention policy (which could be transferred from Uganda – a country 'succeeding' in its fight against HIV/AIDS – to other countries at the global level).

Condoms are a highly effective barrier method that can prevent the transmission and acquisition of HIV at the population-level—and anyone who disputes their efficacy is, in fact, questioning a substantive evidence-base. It can be reasoned that UNAIDS perhaps wanted to highlight the principal significance of increased condom uptake (as the cause of Uganda's HIV decline rather than partnership reduction), as it could subsequently advocate for an effective, evidence-based biomedical product which could be promoted to reduce the transmission and acquisition of HIV at the global level. This notion relates with a finding advanced by Beague et al (2011), who note that external donors often use evidence instrumentally, with evidence itself being shaped by donors' political imperatives to provide generalisable research recommendations, which can be applied systematically and similarly in most countries, and how nationally developed evidence-based policies hold little bearing in countering global policy interests (Beague et al: 2011: pp. 1539). On the basis of findings within this thesis, it can be stated that the partnership reduction explanation emerged when UNAIDS was attempting to establish itself as a competent (and newly formed) UN

international organisation which sought to implement an enhanced global HIV/AIDS prevention model. It can be hypothesised that if UNAIDS had embraced the evidence of partnership reduction (emerging from the analysis of the 1989 and 1995 population-based surveys) in the mid-1990s, it would have questioned its need to advocate for increased financial support to mitigate HIV/AIDS via the distribution of condoms (a clearly-defined and effective HIV prevention policy that was perhaps easier to implement, and transfer across countries, at the global level compared with a partnership reduction based HIV prevention policy).

### *7.3.3 Linking findings with existing understandings of the relationship between evidence and policy*

On the basis of findings presented within this thesis it can be advanced that rational, or linear, understandings of the relationship between evidence and policy can be challenged—especially within Ugandan and global level HIV/AIDS policymaking contexts. Premised on a sequential link between the production of evidence and subsequent policy development, rationalist understandings of the evidence/policy connection are both deterministic and problematically based upon an apolitical understanding of the use of evidence by ‘comprehensively rational’ actors (Cairney: 2014: pp. 1). Findings suggest that HIV/AIDS experts, involved with the creation and analysis of Ugandan evidence, may not have used evidence in a rational or neutral manner. Importantly, HIV/AIDS experts involved with the development of SGS, and explanations for Uganda’s HIV decline, were not unified in their desired policy goals and evidence was not used to fill existing knowledge gaps to create subsequent policy output in an unproblematic manner. Aligning with Young (2002), findings illustrate that rational understandings of the relationship between evidence and policy fail to capture the complex and non-neutral use of evidence by actors who rarely make their decisions on the basis of the best available information (Young et al: 2002: pp. 218). Thus, a rational understanding of the evidence/policy connection should be criticised owing to its static portrayal of the

policymaking process in which evidence is assumed to directly link with subsequent policy output (Monaghan: 2009: pp. 7).

Majone (1989) persuasively reasons that the institutional and political development of policy is always accompanied by a parallel intellectual process of argument and debate, with actors marshalling evidence in support of their own proposals and to challenge the assumptions of their opponents (Majone: 1989: pp. 148). It is also reasoned that actors operating within the policymaking process use evidence to help construct arguments that appeal to the beliefs, values and interests of broader constituencies (Majone: 1989: pp. 148).

Findings presented within this thesis are clearly congruent with the notions advanced by Majone (1989), and the idea that HIV/AIDS experts involved with the development of SGS used evidence in a rational and unproblematic manner is too simplistic. This contention can be advanced as competition, argumentation and politics shaped the evidence/SGS policy relationship which therefore challenges the simple notion that evidence deterministically leads to the production of rational, 'evidence-based policy'—especially within the context of global HIV/AIDS policymaking environments.

Usefully, Weiss (1979) and Kingdon (1995) note that rationalist conceptualisations of the relationship between evidence and policy are not fully comprehensive, as the influence of individual agency, and broader political pressures, present clear challenges to an apolitical use of evidence within an inherently complex policymaking process. Models which depart from rational, or linear, understandings of the evidence/policy connection provide a more nuanced account pertaining to the movement of evidence within the policymaking process and are useful to consider when discussing the role of evidence in Ugandan and global level HIV/AIDS policymaking contexts. In line with Weiss' (1979) political model, evidence supporting the development of SGS was utilised selectively by certain HIV/AIDS experts—perhaps to satisfy their short-term interests (Weiss: 1979: pp. 7). Indeed, evidence has seemingly be used by certain HIV/AIDS experts as

“ammunition” (Weiss: 1979: pp. 429) to help bolster support for predetermined policy positions (i.e. an HIV prevention approach that sought to use condoms as the main tool to reduce the transmission and acquisition of HIV at the global level). Furthermore, it has been demonstrated by statements from interviewees that certain HIV/AIDS experts, in line with Weiss (1979), have potentially used evidence in a political manner to promote one’s individual agency and for reasons of personal aggrandizement within competitive policymaking environments.

#### *7.3.4 Contributions to existing theoretical frameworks attempting to model the relationship between evidence and policy*

Findings from this study can be contextualised within existing theoretical frameworks that attempt to model the relationship between evidence and policy—in particular Stevens’ (2007) evolutionary model. It is the broad analytical objective of this section to relate findings, that emerged via the analysis of SGS, with Stevens’ evolutionary model. More specifically, this section will briefly reiterate key aspects of the evolutionary model and it will explain how elements of the model relate to empirical findings that emerged within the study. Stevens (2007) asserts that existing models of the evidence/policy relationship neglect the tendency for attention to be focused on that evidence which is most helpful to the interests of powerful social groups (Stevens: 2007: pp. 25). He advances an evolutionary analogy to explain how evidence is used in policy development—seeing social structures and political tactics as important in supporting the use of evidence (Stevens: 2007: pp. 28 – 29). Influenced by notions of social Darwinism, it is reasoned by Stevens (2007) that:

A variety of ideas come from evidence and compete for attention in policy, as genes arise and compete for survival...Some of these ideas fit with the interests of powerful groups and some do not. Ideas that do fit will find powerful supporters. Others will not. Those ideas that fit will therefore have groups and individuals that can carry them into policy, as would a gene be reproduced if it finds a place in organisms that survive. The ideas that do not fit will tend not to be picked up by the people who have the

power to translate them into policy. The evolutionary advantage leads to the survival of the ideas that fit (Stevens: 2007: pp. 28).

Stevens maintains that this analogy illustrates the biased use of evidence without depicting policymakers as irrational, or the ability of powerful social groups to implement coordinated campaigns to ignore obstructive research (Stevens: 2007: pp. 28). Reflecting on the analogy above, it can be understood that in accordance with evolutionary social theory evidence comes to inform policy when it aligns with the ideas and objectives of those in positions of power (Monaghan: 2009: pp. 8). Distinct from more linear models (see section 2.3.1), the evolutionary model directs analytical attention to mechanisms of evidence selection and the influence of power upon evidence within the broader policymaking process. It is persuasively reasoned that certain actors, functioning within the policymaking process, have the power to choose those pieces of evidence that most closely align with the interests of powerful groups. Akin to biological theories of evolution, how evidence is selected for use in policy development is messy, complex and occasionally brutal (Stevens: 2007: pp. 28). Stevens' ideas are congruent with Denzin's (2009) realisation that evidence itself is never morally or ethically neutral, with discussions over evidence reflecting underlying contestations of power in terms of who gets to define what counts as evidence, who determines the methods used to generate evidence, and whose criteria are used to evaluate the quality of evidence itself (Denzin: 2009: pp. 142). Helpfully, Stevens (2007) posits five mechanisms via which evidence is selected and used to influence policy, namely: trawling, farming, repetition, flak and strain. Each of these mechanisms of selection will now be defined and used to contextualise empirical findings within this study. In the interests of clarity, Stevens' five mechanisms of evidence selection have been advanced in table form (for a more detailed explanation of the mechanisms of evidence selection refer to section 2.3.4 of the literature review).



Table 7: Mechanisms of evidence selection

<b>Name of evidence selection mechanism</b>	<b>Explanation of mechanism of evidence selection</b>
<b>Trawling</b>	Hauling in bits of evidence that suit the needs of policymakers and throwing back bits that do not.
<b>Farming</b>	Commissioning research but only publishing and using bits of it that meet the criteria set for the flavour and look of the evidence created.
<b>Repetition</b>	Repeatedly referring to bits of evidence ripped out of context and based upon methodologically suspect research. Repetition permits suspect evidence to become part of the accepted body of knowledge in a policy area.
<b>Flak</b>	Used by powerful actors to silence, discredit or attack evidence that comes into the public arena.
<b>Strain</b>	Used by powerful actors upon organisations and individuals that produce and advocate unhelpful evidence. Production of unhelpful evidence by weaker actors not conducive to a successful career or organisational survival.

(Table information from: Stevens: 2007: pp. 28).

In relation to trawling findings indicate that more powerful actors within UNAIDS hauled in bits of evidence, emerging from the analysis of Ugandan sexual behavioural change data – in particular evidence of increased condom uptake – and threw back bits of evidence that did not align with prevailing ideas about global HIV/AIDS prevention (and the desire to implement a multisectoral response to mitigate HIV/AIDS via the distribution and promotion of condoms). The experience of Rand Stoneburner, a former GPA/UNAIDS epidemiologist, maybe seen as an example of strain as more powerful actors within UNAIDS purportedly terminated his employment during the GPA/UNAIDS transition (as the evidence of partnership reduction conflicted with the need to highlight an increased condom uptake explanation that could be used to account for the declining HIV trends within Uganda).

As described above power is key to the precepts of the evolutionary model. Findings demonstrate that Michel Caraël, the former head of HIV prevention within UNAIDS, possessed the requisite power to control how evidence was selected to inform HIV/AIDS policy output and explanations for Uganda's HIV decline advanced by UNAIDS in the mid to late-1990s. Michel Caraël arguably used farming and repetition to draw attention to useful Ugandan evidence (that aligned with the broader political and policy interests of UNAIDS), whilst encouraging the ignorance of inconvenient evidence that did not align with the evolving institutional and political orthodoxy within UNAIDS from 1996 onwards. Pertaining to farming, fragments of research findings (i.e. evidence of increased condom uptake) were published by Michel Caraël within UNAIDS and peer-reviewed literature in the mid-1990s (namely Asiimwe-Okiror et al: 1997). In contrast, the competing reduction in multiple partnership reduction explanation was not widely disseminated during the same period of time. Thus, fragments of evidence were published by an institutionally powerful actor within UNAIDS—fragments that aligned with new ideas about global HIV/AIDS prevention.

Repetition was also arguably utilised as a mechanism to reinforce one interpretation of the evidence for Uganda's HIV decline. The explanation of

increased condom uptake (which could account for the emerging signs of HIV decline within Uganda) was repeated in UNAIDS/WHO policy documentations and peer-reviewed publications in the mid to late-1990s (unlike the reduction in multiple partnerships explanation, which was not widely disseminated until 2004). Indeed, within a document co-authored by Elizabeth Pisani and Michel Caraël (UNAIDS: 1998a), it is claimed that Ugandan sexual behavioural surveys were demonstrating that younger age groups within urban areas were “delaying sexual activity and using more condoms than in the past” (UNAIDS: 1998a: pp. 3). Furthermore, within ‘A Measure of Success in Uganda – The Value of Monitoring both HIV Prevalence and Sexual Behaviour’ (UNAIDS: 1998b) increased condom uptake within the Ugandan population is claimed to be the principal behavioural change that occurred in Uganda between 1989 and 1995 (UNAIDS: 1998b: pp. 10). It is purported by UNAIDS (1998b) that condom use increased from 15% to 55% for men and from 6% to 39% for women (UNAIDS: 1998b: pp. 10). UNAIDS also claim, on the basis of an analysis of 300 smaller-scale sociological studies (conducted by medical anthropologist Tom Baron under the direct instruction of Michel Caraël) that condom use increased among sexually active individuals between 1987 and 1996 from 3% to 25% (UNAIDS: 1998b: pp.10). An additional reflection of a condom-based explanation that could account for Uganda’s HIV decline is located within Asiimwe-Okiror et al (1997) that was published in the journal AIDS in 1997.

It is asserted by Asiimwe-Okiror et al (1997) that women and men reported a 30% and 40% increase in the experience of condom use respectively. It is also claimed that the observed declining trends in HIV correspond to a change in sexual behaviour and condom use (Asiimwe-Okiror: 1997: pp. 1157). Thus, these authors point to increased condom use as *the* most significant sexual behavioural change explaining declining trends in HIV seroprevalence among pregnant women who attended ANC’s within urban areas of Uganda. Significantly, the study concluded that the sexual behavioural change findings “should encourage AIDS control programmes to pursue their prevention activities” (Asiimwe-Okiror: 1997: pp. 1157) which would - on the basis of this contested evidence - include the promotion of condoms. Thus,

this explanation can be understood as an example of repetition as advanced by Stevens (2007).

## 7.4 Study limitations

The two sub-sections below reflect upon the limitations of the study. It commences with an examination of the sample size within the research project. A critical discussion of researcher reflexivity, and how my own actions, values and perceptions impacted upon the research process will also be advanced.

### *7.4.1 Sample size of the research project*

As stated in the methodology chapter, it must be acknowledged that the sample size of the research project means that definitive statements about the Ugandan HIV decline of the 1990s, its contested nature, and the role of behavioural evidence used to shape the direction of HIV prevention policy in the 1990s cannot be advanced. While 29 HIV/AIDS experts who were directly involved with the development of SGS and the analysis of the original sources of evidence used to create formative explanations for Uganda's HIV decline have been interviewed, at least four other key participants within UNAIDS/WHO declined to be interviewed as part of this research project. Furthermore, certain participants who were given the right to reply to some of the highly personalised claims pertaining to the misinterpretation of Ugandan behavioural evidence, did not avail themselves of this opportunity. The absence of narratives from other HIV/AIDS experts – especially within UNAIDS/WHO – means that a degree of uncertainty exists in relation to the analysis of Ugandan sexual behavioural change data in the 1990s. Although certain key HIV/AIDS experts declined to be interviewed as part of this study, the researcher remains confident that key perspectives are adequately represented and that the contours of the Ugandan HIV decline and the debate surrounding the interpretation of behavioural evidence are comprehensively described.

While multiple attempts were made to increase the sample size of the research project both in person and via email, the inability to increase the sample size of this project means that future research should be conducted and additional efforts made to gain more empirical data for analysis. Despite this limitation, the sample size of the research project is of sufficient quality and quantity to make inferences about the contestation surrounding the analysis of Ugandan behavioural evidence and its subsequent use in HIV prevention policy in the 1990s.

#### *7.4.2 Maintaining researcher reflexivity*

It must be acknowledged that my own actions, values and perceptions will have impacted upon the context within which research was conducted, the process of data collection, knowledge construction and subsequent data analysis (Gerrish & Lacey: 2006: pp. 23). While the researcher reflected upon his underlying values and perceptions – especially during data collection – it must be realised that the empirical findings generated in this project have been coloured by my own subjectivism which limited my ability to maintain critical distance.

At times it was difficult for the researcher to stand back from certain narratives that arose during interview—in particular narratives that related to the misinterpretation of the multiple partnership reduction explanation, and the politics surrounding the evidence used to support SGS (and formative explanations for Uganda’s HIV decline). During the context of the semi-structured interviews, the researcher found it difficult to internalise the claims of evidence misinterpretation. While the researcher was conscious of his actions during data collection, it must be noted that the process of interaction (between the researcher and certain participants) was influenced by the researcher’s initial reaction to the complex claims relating to the function of Ugandan evidence and the development of SGS. Significantly, the claims of Ugandan evidence misinterpretation questioned certain preconceptions about the function of HIV/AIDS experts operating within

international organisations (including a preconceived notion that experts should utilise evidence in a non-political and consensus-based fashion). While the researcher was aware that evidence can be used for political or strategic purposes (in advance of data collection), the claims that certain sources of evidence were misinterpreted by HIV/AIDS experts within UNAIDS influenced one's ability to be wholly reflexive within the context of the semi-structured interviews.

It was also difficult to stand back from certain participants on an emotional level during interview. Various participants, interviewed within UNAIDS/WHO, were visibly very upset when discussing the political nature of the Ugandan HIV decline and their narratives pertaining to the misinterpretation of sources of Ugandan behavioural evidence. It must be noted that it was difficult for the researcher to divorce himself from the emotive atmosphere that manifested during interview. It was known, in advance of the interviews, that the kind of interactional exchange between the interviewer and the participant directly affects the process of knowledge construction (and thus the process of data analysis and, in turn, the subsequent validity of data). It must be noted that the researcher reacted to certain narratives on an emotional level during certain interviews which affected my ability to be reflexive and to maintain my critical distance. This was a clear limitation as emotions shaped the researcher's partiality and the direction of the interview, which thus, influenced the researcher/participant dynamic and the subsequent process of data analysis.

## 7.5 Strengths of study

As noted in section 7.3.2, a central strength of this study is the empirical data it presents reflects the researchers' access to an elite of HIV/AIDS experts from Ugandan and Genevan policymaking contexts—experts who were directly involved with creating novel global HIV/AIDS surveillance policy and formative explanations of Uganda's HIV decline in the 1990s. Beneficially, the HIV/AIDS experts interviewed within this project were

open in their discussions about the policy development of SGS and the role of evidence used to support its introduction. This level of transparency – especially during interview – permitted detailed narratives to unfold which, in turn, enabled meaningful partnerships between the interviewer and the participants to develop. Meaningful partnerships with the HIV/AIDS experts ultimately led to context-rich insights into the development of SGS, the reasons supporting its initiation and the complex role of evidence in facilitating its formal introduction in 2000.

It must also be noted that many of the experts interviewed within this project have been directly involved with HIV/AIDS prevention and HIV/AIDS surveillance policy development at the Ugandan and global levels since the late-1980s/early-1990s onwards. It was a genuine privilege to learn about SGS's development (and how evidence was used to support its introduction) from an elite of HIV/AIDS experts who were the first individuals to analyse the formative signs of Uganda's HIV decline, the first to disseminate the emerging HIV decline 'success' story, and the first to create updated global HIV/AIDS surveillance policy guidelines on the basis of behavioural evidence emerging from Uganda. Significantly, many of the HIV/AIDS experts interviewed within this project catalysed change in approaches to global HIV/AIDS prevention, global HIV/AIDS surveillance, and more broadly global HIV/AIDS governance. Thus, the data generated about SGS, and its evidence-base during interview, were usefully contextualised within participants' relevant experiences of wider political and institutional change in relation to HIV/AIDS at both the Ugandan and Genevan levels. Having secured access to key HIV/AIDS experts involved with the development of SGS, it can be stated that the findings presented within the three preceding chapters are context-rich and appear empirically sound.

An additional strength of the thesis was having direct access to a relatively compact body of UNAIDS/WHO policy literature that listed the key sources of documentation pertaining to the development of SGS in 2000—which was available online via the WHO website. Having direct access to official UNAIDS/WHO documentation, that explained the development of SGS in

the formative stages of the research project, permitted the researcher to gain detailed understandings of SGS's development (and the background to the Ugandan HIV prevalence decline) prior to the commencement of data collection in Geneva and Kampala. The critical analysis of official UNAIDS/WHO policy documentation, enabled the researcher to observe the frequency of recurring concepts and themes, which, in turn, facilitated a much needed intellectual command of the 'official' history of SGS which proved to be beneficial during data collection. Possessing an analytical command of official UNAIDS/WHO policy documentation, and gaining access to some of *the* key experts involved with the genesis of SGS, and its underlying evidence-base, were two central strengths of this thesis. The access to official UNAIDS/WHO documentation and key HIV/AIDS experts led to creation of novel, context-rich insights of SGS's development, and the subsequent identification of factors that affect the relationship between evidence and policy within HIV/AIDS policymaking environments at the national and global levels.

## 7.6 Implications for evidence-based policymaking at the Ugandan and global levels

Findings presented within this thesis suggest that the notion, and practice of, EBPM can be critiqued within Ugandan and global level policymaking contexts. For approximately the past twenty years, EBPM has gradually transferred from one policymaking domain to another becoming an aspiration of governments within HICs and more recently international development agencies (Botterill & Hindmoor: 2012: pp. 367). Reminiscent of 1950s policy rationalism and logical positivism, EBPM seeks to ground policy formation in the 'right' evidence to provide decision-makers with the 'best' information about 'what works' in order to temper the influence of ideology, personal beliefs and politics upon policy formation (Botterill & Hindmoor: 2012: pp. 367). Despite an extensive body of literature which queries the rationalist assumptions of EBPM, this vague and aspirational term, which should be conceptualised as an idealised form of policymaking (Cairney:



2014: pp. 1), has spread to global epistemic communities within UN organisations. Indeed, at the 51<sup>st</sup> World Health Assembly (WHA) held in May 1998, it was declared that all member states should “adopt an evidence-based approach to health promotion policy and practice, using the full range of quantitative and qualitative methodologies” (WHA: 1998). This notion was echoed at the ninth plenary meeting of the 59<sup>th</sup> WHA held on May 25<sup>th</sup> 2005, where it was declared that member states should:

Establish or strengthen mechanisms to transfer knowledge in support of evidence-based public health and health-care delivery systems, and evidence-based health-related policies (WHA 58.34: Section II (5): 2005).

Again, the imperative to promote EBPM was reaffirmed in 2010 at the 63<sup>rd</sup> WHA which urged member states to:

Promote intersectoral collaboration and high-quality research in order to produce the evidence necessary for ensuring that policies adopted in all sectors contribute to improving health and equity (WHA 63: Section II (6): 2010).

It was also declared that member states, partners and the Secretariat of the WHO should enhance existing mechanisms for good research and practice, including the proper utilisation of evidence to inform the development of guidelines (WHA 63: Section II (6): 2010). As is clear, the notion and practice of EBPM, and more broadly EBPH, have become well-established within UN organisations. The direct establishment of EBPM can also be witnessed within the context of sub-Saharan Africa. Indeed, EBPM is being promoted as an ‘enhanced’ form of policymaking by international organisations and international development agencies who operate within sub-Saharan African contexts. The normative and political commitment to EBPM is demonstrated via a plurality of donor driven initiatives—which are promoted from HICs and applied in LICs within sub-Saharan Africa. Such evidence-based initiatives include:

- The London School of Hygiene and Tropical Medicine 'Getting Research into Policy Practice' (GRIPP) program which attempts to "improve the practice of evidence informed health policy through the application of political, institutional and sociological analysis" (LSHTM: 2015).
- The WHO's Evidence-Informed Policy Network (EVIPNet) which attempts to promote the systematic use of health research evidence in policymaking focusing on LMICs. The network specially seeks to enhance partnerships at the country-level between researchers, policymakers and civil society in an attempt to facilitate both policy development and policy implementation through the utilisation of the best scientific evidence available (EVIPNet: 2015).
- The WHO's Supporting the Use of Research Evidence (SURE) for policy in African health systems which attempts to support the WHO to strengthen evidence-informed policy-making in Africa (WHO: 2016).
- The Regional East African Community Health (REACH) policy initiative (advanced by the East African Community) which attempts to link health researchers with policymakers and other vital research users—connecting these constituencies via shared and dynamic platforms that support, harmonize and stimulate evidence-based and evidence-informed policymaking processes in the East African region (East African Community: 2015).
- The ODI's Research and Policy in Development Programme (RAPID) programme which attempts to enhance the integration of research-based evidence and local knowledge into policy-making by working with: researchers, think tanks, civil society, donors and governments to develop capacity for policy influence and evidence-informed policy-making (ODI: 2015).

As is clear, a range of external actors from HICs operate within the context of sub-Saharan Africa in order to promote the notion, and practice of EBPM. However, on the basis of empirical findings advanced within this thesis, it must be stated that the promotion of EBPM by external actors within sub-Saharan Africa and global level contexts is perhaps misguided. This contention can be advanced as EBPM is premised upon the assumption that evidence moves within the policymaking process in an essentially linear, unproblematic and neutral manner. EBPM also rests on the normative assumption that actors operating within the policymaking process *should* use evidence in a neutral and apolitical fashion—which clearly is not an accurate depiction of policymaking given the findings presented above.

Such rationalist notions demonstrate a naïve understanding about the use of evidence within the policymaking process and demonstrate a failure to understand the multidirectional, and inherently complex nature of policymaking itself. While it can be asserted that evidence often informs policy it is not appropriate to assume that policy development can be fully evidence-based, and that actors (both individual and institutional) function in a comprehensively rational manner which subsequently leads to the development of ‘evidence-based’ policy. The successful implementation of EBPM and EBPH, pertaining to sub-Saharan African and global level contexts, can be questioned given the following statements that were advanced by HIV/AIDS experts from Ugandan and Genevan contexts:

Table 8: Empirical findings that query the notion and practice of EBPM in Ugandan and global level contexts

Participant	Comment on the function of evidence & data
Dr Txema Garcia-Calleja	Policy...I'm not just talking about HIV, I'm talking about a person with experience working as a public health doctor in the last 30 years in developing countries and it's not always the case...often policy is not done on evidence...I think economic interests and personal interests sometimes overrides evidence.
Professor Daniel Tarantola	I have my own perspective on the use of data by decision-makers. I think that the extent to which decision-makers are actually basing their decisions on data is very limited.
Professor David Serwadda	It's amazing. Beliefs and attitudes trump any knowledge... evidence...anything it's all belief driven. It's values and beliefs that's it. If evidence is in my direction of beliefs...I'll report it, that's what I'll put forward. If it's not it will never show up.

The findings displayed within the table above indicate that the notion, and practice of, EBPM within sub-Saharan African and global level policymaking contexts is possibly unrealistic. These notions suggest that policy is developed in the absence of evidence, with policy being more directly determined by personal beliefs, individual values and broader economic concerns. These notions are unsurprising to those analysts who comprehend that evidence is frequently created, analysed and disseminated by individual actors in a political manner in order to exercise their power within complex institutional environments (Weiss: 1979: Denzin: 2009: Kingdon: 1995).

However, the normative allure of EBPM (and the ideal of rational evidence utilisation) are so strong that international organisations and international development agencies are willing to pursue the goal of EBPM – and indeed to promote this idealised form of policymaking within the context of sub-Saharan Africa. The wish to promote EBPM arguably underestimates how evidence is inextricably interlinked with power-based discussions over what counts as evidence, the political actions of individuals tasked to analyse evidence, and the social construction of expertise (and evidence itself) within complex institutional environments. Findings in this thesis have demonstrated that sources of evidence, within Ugandan and global level policymaking contexts, have been shaped by a perplexing array of process and strategies which illustrate the gritty realism of evidence utilisation among HIV/AIDS experts functioning in sub-Saharan African and global level contexts. The empirical findings presented in the three preceding results chapter should serve as a reminder that the application of EBPM, in sub-Saharan African contexts by external actors, should be questioned as competition and politics appear to determine evidence/policy relationship more readily than logic and partisanship.

## 7.7 Directions for future research

Findings within this thesis point towards three areas for future research. First, research that further examines the competitive and political nature surrounding the Ugandan evidence used to support the development of SGS and formative explanations of Uganda's HIV decline of the early to mid-1990s. Second, research that could potentially lead to theoretical contributions to Stevens' (2007) evolutionary model via the creation of an additional mechanism of evidence selection. Each of these two directions for future research will now be discussed.

Results have demonstrated that Ugandan evidence, used to support the development of SGS and explanations for Uganda's HIV decline, have been influenced by an array of complex processes and strategies among

HIV/AIDS experts operating within competitive policymaking networks at the Ugandan and global levels. While findings indicate that certain sources of Ugandan evidence have been purportedly misinterpreted (as certain constructions of evidence failed to align with adaptations in the prevailing institutional and political orthodoxy at the global level in the mid-1990s), the underlying reasons contributing towards the political use of evidence remains analytically incomplete. While explanations were advanced by certain participants who introduced the notion of a political use of evidence within Ugandan and global level policymaking contexts, an array of narratives from other HIV/AIDS experts – who were involved with the development SGS and global HIV/AIDS prevention – were not captured within this research project (owing to time and budgetary constraints). Analysis suggests that additional HIV/AIDS experts should be interviewed in the future to help clarify the narrative of Ugandan data misinterpretation and the political use of evidence within HIV/AIDS policymaking networks at the Ugandan and global levels. On the basis of data analysis, potential interviewees for future research should include the following:

Table 9: Future participants to interview

1. Peter Piot – former Executive Director of UNAIDS.
2. Bernhard Schwartländer – former Director for Evidence, Policy & Innovation in UNAIDS/former Director of the WHO's HIV department/former Director of Evaluation & Strategic Information in UNAIDS.
3. Ties Boerma – Director of the Department of Health Statistics and Information Systems in the WHO.
4. Tom Barton – Medical anthropologist & researcher employed by Michel Caraël to review evidence of sexual behavioural change in Uganda in the mid-1990s.
5. Knut Fylkesnes – Epidemiologist & lead researcher of Zambian study cited as evidence by UNAIDS to support the idea for concurrent analysis of behavioural surveillance data with serological surveillance data.
6. George Tembo – former epidemiologist for the WHO & former Country Programme Advisor for UNAIDS within Uganda.
7. Godwill Asiimwe-Okiror – lead author of: 'Change in sexual behaviour and decline in HIV infection among young pregnant women in urban Uganda' (1997) & former senior Ugandan Ministry of Health official.
8. Daniel Halperin – HIV/AIDS researcher specialising in HIV prevention current Senior Research Scientist at the Harvard AIDS Prevention Research Project.
9. Helen Epstein – HIV/AIDS researcher, author & HIV/AIDS journalist.

It would be beneficial for future research to interview the aforementioned individuals as a greater degree of analytical information would be generated in relation to the development of SGS and the function of Ugandan evidence used to support its formal introduction in 2000. This, in turn, would provide additional insights into the relationship between evidence and policy within global and Ugandan policymaking contexts and the identification of factors that shape the evidence/policy nexus itself.

A second direction for future research involves the potential creation of an additional mechanism of evidence selection to build upon Stevens' (2007) evolutionary model. Findings indicate that Ugandan evidence of sexual behavioural change have been purportedly misinterpreted within HIV / AIDS policymaking environments. Aligning with Stevens' biological notions, it can be reasoned that 'mutation' could be advanced as an additional mechanism of evidence selection on the basis of the empirical findings generated within this study. Mutation can be understood as a process undertaken by entrepreneurial policymakers to transform fragments of evidence to align with the prevailing political environment. Via mutation, biased evidence can then become part of the accepted body of knowledge in a given policy area. Mutated evidence subsequently diffuses within policymaking networks, with the mutated evidence having a competitive advantage over other forms of evidence which can contribute to the development of subsequent policy in a more efficient manner. The active deployment of mutation by policymakers gives evidence an evolutionary advantage within policymaking environments, and as the mutated evidence has been strategically aligned to fit the prevailing political orthodoxy, or the wider "climate of receptivity" (Kingdon: 1995: pp. 206), policy ideas emerging from mutated evidence can then transmit amongst those involved with policy development. The advancement of 'mutation' as an additional mechanism of evidence selection cannot be posited at this stage—future empirical research is therefore required to validate, or refute, this potential theoretical contribution to Stevens' (2007) evolutionary model.

The third direction for future research relates to the possible application of Stevens' (2007) evolutionary model in other LICs and LMICs when attempting to examine the role of evidence in policy development. The application of the evolutionary model in other geographical locales could help researchers to explore the complex role of evidence in policy development and how the power of various actors operating within LICs and LMICs – in particular international organisations – influence the relationship between evidence and policy. Findings above indicate that Stevens' mechanisms of evidence selection influenced how certain kinds of



evidence informed, or failed to inform, subsequent policy output. It would be fruitful to discover if these mechanism of evidence selection – and the broader precepts of the evolutionary model itself – can be applied when attempting to explore how evidence is used by individuals and institutions operating within policymaking environments in LICs and LMICs.

## **CHAPTER EIGHT: Conclusion**

This thesis aimed to examine contested explanations for the decline in HIV prevalence in Uganda and the role of evidence in the development of global HIV prevention policy via the analysis of SGS. This study demonstrates that the development of SGS, and the politics of evidence supporting its introduction, are more complex than existing UNAIDS/WHO accounts describe. Official explanations of the development of SGS provide a simplistic account of how evidence informed policy in a linear and rational way. In contrast, findings from this thesis suggest that SGS served multiple policy functions (i.e. marketing, promotion of institutional credibility, and a demonstration of disciplinary integration) in the context of the recently-formed UNAIDS, and that the role and interpretation of evidence in this context were highly contested.

Via the critical analysis of SGS it has been demonstrated that the relationship between evidence and policy, pertaining to Ugandan and global level policymaking contexts, is non-linear, competitive, and inherently political. Within global HIV/AIDS policymaking environments it has been demonstrated that evidence can be used in a political manner with constructions of evidence being shaped to align with adaptations in the prevailing institutional and political orthodoxy.

By examining policy entrepreneurship, competition between HIV/AIDS experts, claims of disciplinary bias, and data misinterpretation, and their impact within HIV/AIDS policymaking networks, it can be concluded that existing explanations of Uganda's HIV prevalence decline – as portrayed by UNAIDS in the late-1990s – were contested. Interview data suggest that alternative constructions of Ugandan evidence were available to inform the direction of HIV prevention policy and formative explanations for Uganda's HIV prevalence decline in the 1990s. However, analysis indicates that the available empirical evidence may have been insufficient to definitively support *either* an increased condom uptake explanation *or* a reduction in

multiple partnership explanation as the key reason that could account for Uganda's HIV decline and the subsequent direction of HIV prevention approaches in the 1990s. While the interview data highlighted the contested nature of the Ugandan HIV prevalence decline – and the sexual behavioural change reasons that could account for the decline itself – it is appropriate to acknowledge that the data generated via interviews may have been influenced by recall bias – a widely acknowledged limitation associated with qualitative interviewing.

It can also be concluded that the concept, and practice of, EBPM pertaining to sub-Saharan African and global level policymaking contexts can be called into question. While international organisations may champion the promotion and practice of EBPM, data presented within this thesis appear to indicate that commitments to EBPM could be understood as somewhat rhetorical. While UNAIDS/WHO give the impression of rational evidence utilisation, and directional links between the production of evidence and subsequent policy development, these depictions conceal the complex manner in which evidence is also used to help promote broader political and institutional goals. Empirical findings suggest that researchers (and policy analysts) would benefit from more sophisticated understandings of how evidence does, and does not, influence subsequent policy development pertaining to sub-Saharan African and global level policymaking environments. To understand adequately the relationship between evidence and policy within Ugandan and global level policymaking contexts, it is important to realise that evidence is contingent upon complex social processes and, as Stevens (2007) notes, the broader influence of power within policymaking. Thus, researchers who seek to examine the relationship between evidence and policy within country and global level policymaking contexts, should be aware that politics, argumentation and the complex exercise of power within potentially adversarial policymaking networks are key factors that inform policy development more directly than evidence in its own right.

## Appendix 1: Consent form for participants

### **Part 1: Information about the research project**

**Project title: Second Generation HIV Surveillance in Uganda: A critical analysis**

I would like to invite you to participate in the aforementioned research study. This information sheet explains what this research is and why it is being carried out. **Please read the following information carefully.**

#### **What is the purpose of the study?**

I am asking you to participate in my PhD research project. It seeks to understand the development of Second Generation HIV Surveillance and the evidence-base that supported its introduction in the year 2000. It will, through interviews and document review, attempt to understand the policy development of Second Generation HIV Surveillance.

#### **Why have you been invited to take part?**

I hope to record the views and experiences from as many decision-makers and experts involved with Second Generation HIV Surveillance within UNAIDS & WHO. Through my research it has become apparent that I must target individuals from the above institutions in order to gain the data I need to help the development of my research.

#### **Participation**

Participation in this study is voluntary. Participants are free to withdraw at anytime.

#### **Data handling**

All data generated within this research project will be password protected and securely stored. Audio recorded data and paper files will be secured in a locked desk. Participants are free to request copies of the recorded interviews and transcribed data should they wish. Please email: [dougierichards@gmail.com](mailto:dougierichards@gmail.com) for information requests. All files will be destroyed following the completion of the PhD thesis.

### Issues of Confidentially

All participants who decide to take part in this research project have the right to remain anonymous; participants will be asked whether or not they wish to be identified in my research. Please carefully consider which of the three following options you prefer:

1. You are willing to participate on the basis that all identifiable features will be removed and your participation in the research will not be disclosed. You agree to be quoted given that all quotes will be made anonymous.
2. You are willing to participate on the basis that you will be identified as an interviewee but under the provision that no quotations will be directly attributed to you.
3. You are willing to participate on the basis that you are happy to be identified as an interviewee and for quotation, if used, to be directly attributed to you.

If you request to be made anonymous, all data generated from your interview will be regarded as confidential. The generated data will be viewed by the researcher Mr. Douglas Richards and his two supervisors: Dr Sarah Hill & Dr Jeff Collin (contact details below).

### Contact details

I am the primary point of contact for this research. My contact details are: Mr. Douglas Alexander Richards, PhD International Public Health Policy Research Student, Chrystal Macmillan Building, Room 5.13, School of Social and Political Studies, George Square, University of Edinburgh, UK, Tel: +44 (0) 7545 376 457, [dougie-richards@gmail.com](mailto:dougie-richards@gmail.com)

### Problems or complaints

If you have any problems or complaints please contact my PhD supervisors:

Dr Sarah Hill: [s.e.hill@ed.ac.uk](mailto:s.e.hill@ed.ac.uk)  
Tel: +44 (0)131 650 3884

Dr Jeff Collin: [Jeff.Collin@ed.ac.uk](mailto:Jeff.Collin@ed.ac.uk)  
Tel: +44 (0)131 650 3886

## Part 2: Anonymity & Consent Form

**If you are willing to be interviewed for this research, please complete this declaration, which is a requirement of the University of Edinburgh's ethical guidance.**

**Please tick one of the following boxes, depending on your preference:**

(i) I am happy to be interviewed for this research on the basis that all identifiable features will be removed and my participation in the research will not be disclosed.

☐

(ii) I am happy to be interviewed for this research and to be identified as an interviewee but I do not want quotations to be attributed directly to me.

☐

(iii) I am happy to be interviewed for this research and, if any quotations are taken from the interview and used in research outputs, for these quotations to be directly attributed to me.

☐

I am happy for the interview to be digitally recorded.

☐

YES

☐

NO

**In signing the declaration below, I am declaring that I:**

- have read the participant information listed above;
- have had the opportunity to ask questions about the study and have received satisfactory answers to questions, and any additional details requested;
- understand that I may withdraw from the study at any time by advising the researcher of this decision;
- understand who will have access to the data provided, how the data will be stored, and what will happen to the data at the end of the project;
- agree to participate in the study;
- agree that I will not discuss the details of this interview with anyone outside my own organisation or misrepresent the nature of this interview (which is being conducted purely for research purposes) to others.

**NAME IN BLOCK  
LETTERS** \_\_\_\_\_

**SIGNED (INTERVIEWEE)** \_\_\_\_\_ **DATE**

\_\_\_\_\_

**SIGNED (INTERVIEWER)** \_\_\_\_\_ **DATE**

\_\_\_\_\_

## Appendix 2: Questions advanced during interview

- What was the significance of the Nairobi meeting in 1997 in developing SGS?
- Who attended the Nairobi meeting? Which organisations were involved?
- Who was involved with the introduction of SGS from UNAIDS?
- Who was involved with the introduction of SGS from WHO?
- Who were the key players involved with the introduction of SGS both in terms of people and organisations?
- Can you describe the process by which SGS came about?
- What is the actual evidence base that underpins the introduction of SGS?
- How central was sexual behavioural data from Uganda in supporting the development of SGS?
- Was evidence from Uganda key in supporting the development of SGS?

### Appendix 3: Uganda National Council of Science and Technology Research Clearance form



#### Uganda National Council for Science and Technology

*(Established by Act of Parliament of the Republic of Uganda)*

Our Ref: SS 2648

December 1, 2011

Mr. Douglas Richards Alexander  
Global Health Network  
P.O Box 1131  
KAMPALA

Dear Mr. Richards,

**RE: RESEARCH PROJECT, "SECOND GENERATION HIV SURVEILLANCE IN UGANDA: A CRITICAL ANALYSIS"**

This is to inform you that the Uganda National Council for Science and Technology (UNCST) approved the above research proposal on **October 6, 2011**. The approval will expire on **October 6, 2012**. If it is necessary to continue with the research beyond the expiry date, a request for continuation should be made in writing to the Executive Secretary, UNCST.

Any problems of a serious nature related to the execution of your research project should be brought to the attention of the UNCST, and any changes to the research protocol should not be implemented without UNCST's approval except when necessary to eliminate apparent immediate hazards to the research participant(s).

This letter also serves as proof of UNCST approval and as a reminder for you to submit to UNCST timely progress reports and a final report on completion of the research project.

Yours sincerely,

Leah Nawegulo  
for: Executive Secretary  
UGANDA NATIONAL COUNCIL FOR SCIENCE AND TECHNOLOGY



## Appendix 4: Office of the President Research Clearance Letter



THE REPUBLIC OF UGANDA

### OFFICE OF THE PRESIDENT

PARLIAMENT BUILDING P.O. BOX 7168 KAMPALA, TELEPHONES: 254881/6, /343934, 343926, 343943, 233717, 344026, 230048, FAX: 235459/256143  
Email: secretary@op.go.ug, Website: www.officeofthepresident.go.ug

**ADM 154/212/01**

November 4, 2011

✓The Resident District Commissioner  
Kampala District

This is to introduce to you **Mr. Richards Douglas Alexander** a Researcher who will be carrying out a research entitled "**Second generation HIV surveillance in Uganda: A critical analysis**" for a period of **05 (five) weeks** in your district.

He has undergone the necessary clearance to carry out the said project.

Please render him the necessary assistance.

By copy of this letter **Mr. Richards Douglas Alexander** is requested to report to the Resident District Commissioner of the above district before proceeding with the Research.

Alenga Rose

**FOR: SECRETARY, OFFICE OF THE PRESIDENT**

Copy to: Mr. Richards Douglas Alexander

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